Global meaning in people with spinal cord injury or stroke

Littooij, E.C.

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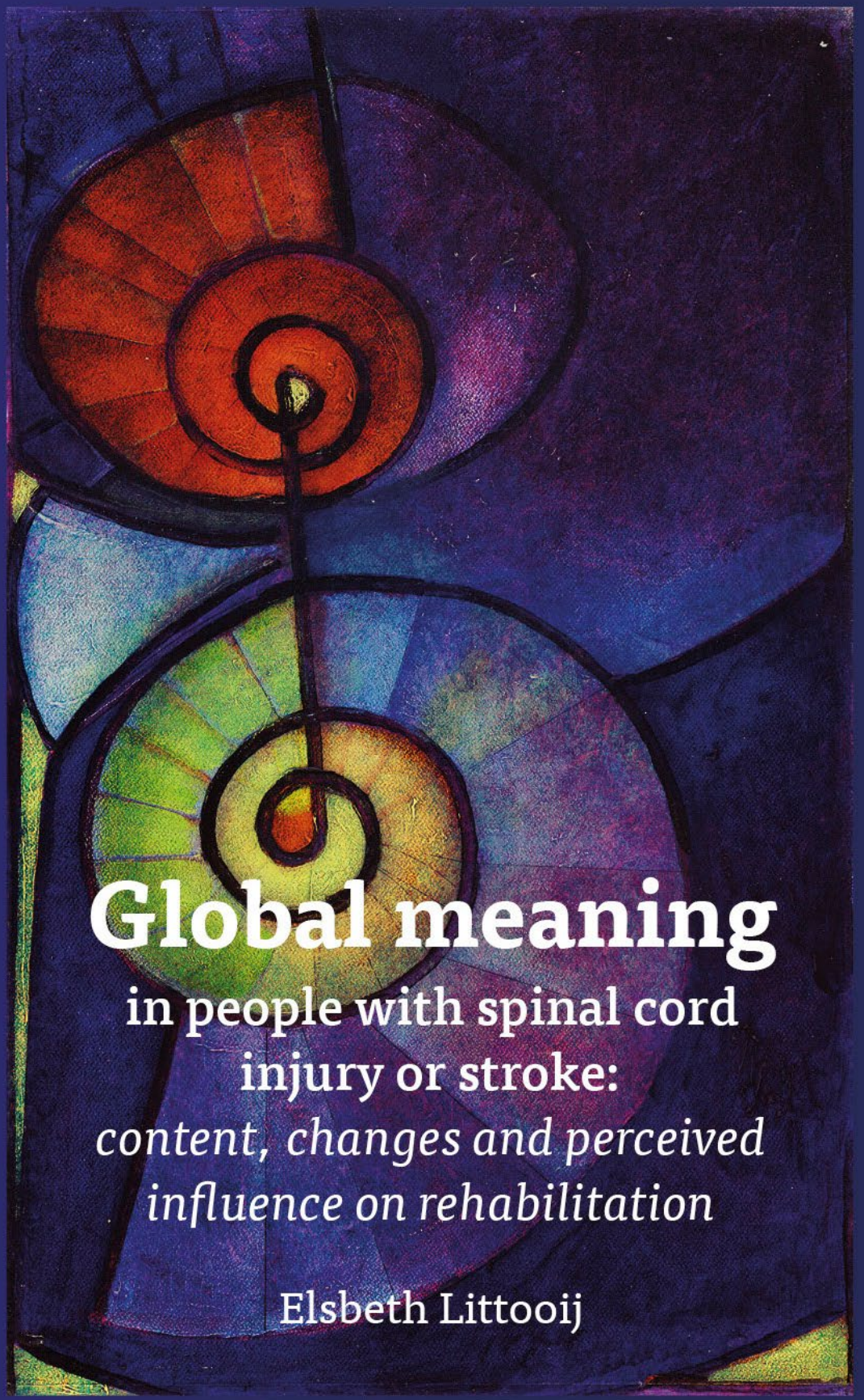

Global meaning

in people with spinal cord injury or stroke:

content, changes and perceived influence on rehabilitation

Elsbeth Littooij

Global meaning in people with spinal cord injury or stroke: content, changes and perceived influence on rehabilitation

Bij het coverbeeld:

Hoe God de Aarde schiep

Het 'Ik' stamt niet uit de hersenen, maar wel worden we daar ons zelf bewust. Kindertekeningen geven een beeld van hoe ons 'Ik' wervelend afdaalt uit de kosmos. Ook ons kruintje is daar een beeld van in de vorm van een spiraal. De allereerste kindertekening die kinderen spontaan maken laat zien hoe ons 'Ik' spiraalsgewijs afdaalt uit de kosmos. In de hele natuur vinden we de spiraal terug. In het hart van een zonnebloem maar ook in het hart van een tornado.
Herman Smith

Colophon

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VRIJE UNIVERSITEIT

Global meaning in people with spinal cord injury or stroke: *content, changes and perceived influence on rehabilitation*

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De engelen *Toen ik bezig was met mijn schilderij 'Engelen drieluik' hoorde ik een engel die mij vroeg: 'Waarom dek je jouw blijdschap af met iets anders?' Het woord 'blijdschap' gebruik ik nooit, dus moet het wel een engel zijn geweest. De engelen zijn dragers van mijn lot. Mijn lot is bijvoorbeeld een beroerte te hebben. Ik ben geen beroerte, maar ik heb die. Het verschil tussen hebben en zijn. Ik ben het niet eens met het boek van Dick Swaab: 'We zijn ons brein'. We zijn onze hersenen niet. We hebben ze! Hersenen spiegelen. Ze geven ons zelfbewustzijn. Maar de spiegel is niet jezelf. Interessant toch?*

Chapter 1

General introduction

After a major physical injury, people are confronted with loss of health and physical abilities. Most people need rehabilitation in order to learn to live with the consequences of their injury. Multidisciplinary teams of professionals help people to find new ways to live with their limitations and to develop new skills in order to adjust to the changes. Besides, or as a result of, the physical challenges, questions of meaning tend to arise when people encounter stressful life events like that.[1-6] To address these questions, healthcare institutions in the Netherlands are obliged by law to provide or give access to chaplaincy or spiritual counseling.[7] In most cases, however, rehabilitation focuses on physical factors, along with psychological and social adaptation,[8,9] and considerably less on questions of meaning. This is understandable, since rehabilitation care is based on the biopsychosocial approach of the ICF.[10,11] Even though this approach is more comprehensive than a strictly medical model, it does not automatically include a dimension of meaning and spirituality. The importance of meaning in rehabilitation is more and more recognized,[12] although research on meaning in rehabilitation is scarce. A better understanding of what meaning can comprise and its role in rehabilitation may be important in supporting people in the process of adaptation to a major physical injury. In our research project, we focused on this somewhat neglected, but important area of rehabilitation.

We focus on two diagnosis groups: spinal cord injury (SCI) and stroke.

Annually, between 250.000 and 500.000 people worldwide suffer SCI,[13] and 15 million people are confronted with a stroke.[14] In the Netherlands this is approximately 400 (SCI)[15] and 41.000 (stroke)[16]. The consequences of SCI and stroke affect all areas of life and often result in permanent changes that make daily life challenging.[6,17,18] After SCI, people report problems with body functions, activities and participation, as well as problems with emotional and sensory functions, and pain. Among other things, living with SCI affects mobility, selfcare, domestic life, and interpersonal interactions and relationships.[19] Living with a stroke can result in different combinations of physical, cognitive, emotional and behavioral problems, which may have implications for all areas of life including practical, social and vocational aspects.[3,18,20] Among the reported effects are the experience of identity changes and social isolation.[20-23] SCI as well as stroke create considerable discontinuity in a person's life. Each person with SCI or stroke reacts to this challenge in their own way. Some adapt seemingly easily, others experience more difficulty adapting, or distract from society.[6,9,24] However different, people need to find a way to live a meaningful life again.

Both people with SCI and people with stroke face the challenge of living a life 'that will never be the same'. The consequences of both SCI and stroke are in most cases permanent. However, people with SCI face mostly physical consequences, whereas people with stroke may be confronted with consequences in the areas of cognition and personality as well. In our study, we started with exploring meaning and its relation to rehabilitation

in people with SCI, because they are confronted with primarily physical challenges. In a second stage of the study we expanded this to people who were confronted with even more complex challenges, such as the cognitive and personality consequences a stroke may entail. This also gave us the opportunity to compare both groups. We were open to the possibility that meaning could appear differently in both groups.

Global meaning

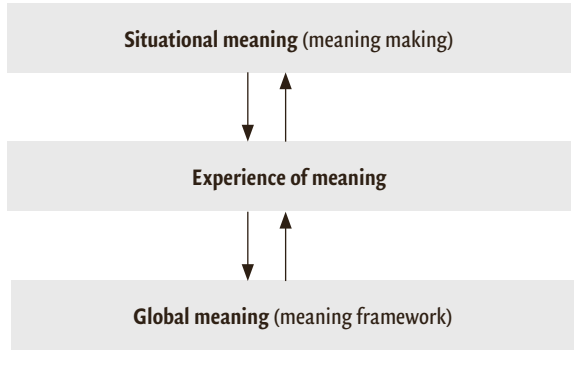
What do we mean when we speak about meaning? In an extensive review of the meaning literature that comprises more than 25 years of research on meaning in relation to stressful life events, Park developed a meaning making model.[4] This model has been representative in the field of coping with stressful life events since the first preliminary version of it in 1997.[25] With this model, she describes the way in which people search for or develop meaning, when confronted with a stressful life event. In her model, Park distinguishes two levels of meaning: global meaning and situational meaning. *Global meaning* is the more fundamental level of meaning. It refers to general orienting systems, that guide people in living their lives. According to Park, global meaning consists of global beliefs, global goals, and subjective feelings. It influences individual's general levels of health, and plays an essential role in meaning making processes.[5] *Situational meaning* denotes meaning in a particular situation. It comprises meanings that people appraise to a particular stressful life event, and psychological meaning making processes that occur when the appraised meanings differ from a person's global meaning. According to Park, meaning making is discrepancy based. When there is a discrepancy between appraised meaning and global meaning, this sets in motion meaning making processes, in order to diminish the stress of the discrepancy. These psychological processes seek to integrate stressful life events by adapting to the new circumstances (assimilation) or by changing global beliefs and goals (accommodation). Ideally these processes lead to meanings made: changes in appraised meaning, changes in global meaning, or stress-related growth.[4,5]

Using different terminology, Mooren makes a distinction similar to the distinction between situational and global meaning. He distinguishes between the level of 'meaning making' (situational meaning in terms of Park), and the 'meaning-framework' (global meaning in terms of Park). With *meaning making* Mooren refers to psychological processes, concerning cognitive (self)regulators, such as goals, values, and notions of manageability. The *meaning-framework* comprises elements of philosophies of life, such as worldview, ethics and views on suffering. Besides that, Mooren explicitly presents a third level of meaning: the *experience of meaning*, which comprises e.g. experiences of comprehensibility, competence, and peace of mind.[26]

In Park's model, there is no separate level of meaning-experience. Following Mooren, we regard the experience of meaning as a different level of meaning. Distinguishing a separate level of meaning-experience can be helpful in understanding the varying ways in which meaning is addressed in literature and research. In Park's meaning making model, the focus is on situational meaning, or meaning making processes, in which

global meaning plays an important role. The aspect of experience can be found partly in global meaning, as 'a subjective sense of meaning' and partly in situational meaning, as 'meanings made'. Several other researchers focus primarily on the experience of meaning.[27-31] Thus, we believe that conceptually it is helpful to distinguish between global meaning, situational meaning, and experience of meaning. The three levels of meaning are illustrated in Figure 1. In our research, we focus exclusively on global meaning or the meaning framework, which is the area of expertise of healthcare chaplains.

Figure 1: *Levels of meaning (derived from Mooren (1997))*[26]



Research on meaning

Scientific attention for meaning and spirituality and their role in adapting to a stressful life event such as a stroke or SCI, is growing.[1-6,12,24,32-34] It is important to note that meaning and spirituality are overlapping, but distinguished concepts. Literature on meaning shows that this research field concerns complex concepts, on which there is little consensus regarding their definitions.[34]

Especially in the fields of palliative care[35-38] and nursing,[39] spirituality has been found to play an increasingly important role. In 2002, Sulmasy proposed an expansion of the current biopsychosocial model in healthcare, to a biopsychosocial-spiritual model.[40] However, in rehabilitation, meaning and spirituality are only recently becoming a matter of interest.[41] The majority of studies are psychological studies that focus on *situational meaning*. These studies concern the psychological processes concerned with adapting to a stroke or SCI, i.e. meaning making processes. In addition, the number of instruments to measure meaning is increasing; examples include the meaning in life questionnaire,[27] or the purpose in life scale,[42] among others.[28,43-45] These instruments study the *experience* of meaning. In the meaning in life questionnaire, for example, one of the questions is: 'I am always searching for something that makes my life feel significant'.[27] Global meaning

is sometimes measured as well, but also in these cases, what is studied is the experience of (global) meaning.[29-31] To our knowledge, there is a lack of in-depth research on the *content* of global meaning. Therefore, we focused on the content of global meaning in people with SCI or stroke.

Rehabilitation and global meaning

Rehabilitation is a complex and interdisciplinary field of healthcare. Teams of professionals from different backgrounds such as medical sciences, nursing, psychology, occupational therapy, physical therapy and social work, work together to help people adapt to their changed possibilities. According to the Netherlands Society of Rehabilitation Medicine, rehabilitation aims at improving functions and abilities, optimizing independence, self-direction and participation of patients with impairments as a result of a congenital or acquired disorder. Rehabilitation focuses on the consequences of these disorders for the patient and on promoting quality of life. In rehabilitation, personal factors and external factors of the patient (such as the living environment) play an important role; therefore they are explicitly taken into account in the treatment plan.[46] Although global meaning is considered to be a personal factor,[47] in rehabilitation it is scarcely taken into account.

Global meaning may be a resource in helping people to adjust after SCI or stroke. Both Park and Mooren mention a relation between global meaning (or the meaning framework) and behavior, adaptation, and motivation. Park states that global meaning 'provides people with cognitive frameworks with which to interpret their experiences and with motivation' and that global meaning 'appears to powerfully influence individuals' thoughts, actions and emotional responses'.[4] Mooren states that the meaning framework facilitates the application of structure and coherence in people's experiences, and that it provides guidelines for behavior.[26] In an exploration of psychological adjustment to chronic disease, Dekker and de Groot state that disease leads to acute and ongoing illness stressors that induce cognitive, emotional and behavioral responses. According to Dekker and de Groot, personal background factors (e.g. global meaning) influence the experience of acute and ongoing stressors, as well as the cognitive, emotional and behavioral responses to these stressors.[47] Hence, we can hypothesize that global meaning may be of influence on processes and outcomes of rehabilitation. Rehabilitation processes include dealing with stress, gaining motivation, and the interaction between therapist and patient, among other processes. Assuming that these processes are influenced by global meaning, it is likely for outcomes of rehabilitation to be influenced as well. Outcomes include being able to take care of one's personal needs or work, among other outcomes. In our research project, we focused on the relation between global meaning and the processes and outcomes of rehabilitation.

Chaplaincy research

The Dutch Association of Chaplains in Healthcare Institutions describes the role of the healthcare chaplain as follows: "Chaplains come into view when the self-evident order of everyday life is broken; in situations of life and death, in the event of farewell and loss, in the case of experiences of great connection or of abandonment, and in ethical questions. They are proficient in dealing with life questions, meaning, spirituality and ethical considerations. Chaplaincy is professional support, assistance, and advisement concerning meaning and philosophy of life."[48]

Since chaplains are pre-eminently qualified to address questions of meaning and spirituality, one would expect research in this area to be conducted especially by chaplains. However, in many healthcare institutions, a chaplain is a valued colleague, but not many of them are also involved in research. Most research in the area of spirituality and meaning is conducted by physicians, nurses and psychologists. And if research is conducted by chaplains, it is mostly research on the role and efficacy of chaplaincy.[49-52] Besides that, the influence of spirituality and religiosity on health is studied[53-56] and spiritual assessment tools are developed.[57,58] Interest of chaplains in research is growing. The importance of being familiar with research and contributing to it, is more and more recognized.

In June 2017 the launch of the European Research Institute for Chaplains in HealthCare (ERICH) took place, with participants from 32 countries. The goals of ERICH are to initiate research to inform the best possible spiritual care by healthcare chaplains for patients, their loved ones and staff; to promote the importance of research in spiritual care by healthcare chaplains; to provide education, resources and mentorship for healthcare chaplains interested in spiritual care research; to seek collaboration and dialogue with research orientated institutions and individuals globally; and to translate, publish and disseminate existing research in spiritual care by chaplains. Our research project was one of the projects that were presented at the launch of ERICH. It did not entirely fit the goals, in that it is more comprehensive in orientation. We study global meaning, which is related to, but to be differentiated from spirituality, and we focus on the impact of global meaning on processes and outcomes of rehabilitation, and not on chaplaincy per se. Our research project concerns research in the field of expertise of chaplains, conducted by a chaplain, but aimed at global meaning and rehabilitation.

Our project took place in a complex interdisciplinary context in which disciplines informing chaplaincy, such as theology, philosophy and religious studies encounter medical rehabilitation disciplines such as psychology, social work, occupational therapy, nursing and physical therapy. In a complex interdisciplinary research field like this it is important to bear in mind the differences of the disciplines and their backgrounds, and to be aware of the specific contribution of each discipline in this context.

Aims of our project

The goal of our project was to study global meaning in people rehabilitating from spinal cord injury or stroke. It addresses two related research questions: (i) the content, as well as perceived continuity or change of global meaning in people with spinal cord injury or stroke and (ii) the perceived influence of global meaning on processes and outcomes of rehabilitation according to people with spinal cord injury or stroke.

Since the content of global meaning is scarcely studied in the field of rehabilitation, we aimed to investigate the content of global meaning in people with SCI and people with stroke, and its perceived continuity or change. Following a grounded theory approach, we interviewed people and analyzed the interviews, searching for aspects of global meaning. Also, we tried to find out whether respondents perceived their global meaning to have changed after their injury, or if it possibly was a source of continuity amidst the discontinuity caused by their injury.

To our knowledge, the relation between global meaning and processes and outcomes of rehabilitation has not been studied before. Therefore, we aimed to discover whether and how respondents connected their global meaning with processes or outcomes of their rehabilitation, and with what processes and outcomes.

In the first phase of our research project, we identified five aspects of global meaning: core values, relationships, worldview, identity, and inner posture. Because inner posture was a concept not previously mentioned in scientific literature, we aimed to elaborate on this potentially new concept by relating it to four concepts in healthcare literature that seemed to address a similar phenomenon. We choose a hermeneutical approach in this confrontation, aiming at clarifying and enriching our understanding of the phenomenon at stake.

Our project intends to contribute to knowledge on global meaning and the role it plays in rehabilitation. We expect that our project will give an impulse to incorporating the concept of global meaning in rehabilitation practice.

Outline of this thesis

This thesis comprises five chapters that were originally written as separate articles.

In **chapter 2** we address the content as well as the perceived continuity or change in global meaning in people with spinal cord injury (research question (i)).

In **chapter 3** we explore the role global meaning plays in processes and outcomes of rehabilitation, according to people rehabilitating from spinal cord injury (research question (ii)).

Chapter 4 addresses global meaning in people with stroke, content as well as the continuity and/or changes they experience (research question (i)).

In **chapter 5** we address global meaning and rehabilitation in people with stroke (research question (ii)). Which aspects of global meaning have an impact on which processes and outcomes of their rehabilitation, according to people with stroke?

In **chapter 6** we zoom in on one of the aspects of global meaning we identified in the first part of our study, namely inner posture (research question (i)). Using a hermeneutical approach, we ask ourselves what exactly is this phenomenon we refer to as inner posture. We seek to clarify and enrich the concept and our understanding of it, by confronting it with four related concepts in healthcare literature.

An overall discussion of the findings of this thesis is provided in **chapter 7**. This chapter offers links between the five separately written and published articles in chapters 2-6 and elaborates on the findings of this thesis, placing them in a broader perspective.

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De schoenen van het lot *Niemand wordt door de beroerte getroffen op dezelfde manier. Niemand kan in de schoenen van een ander staan. Ook hoe iemand op zijn of haar beroerte reageert is telkens anders. Ook of iemand oud of jong is maakt een aanmerkelijk verschil. Laatst vroeg ik: Wil je mijn lot ruilen met jouw lot? En zijn antwoord was: 'O nee!' Ieder draagt zijn lot. Iedereen is vrij om te weten of zijn lot een noodlot is. Zoals ieder zijn eigen schoenen draagt.*

Chapter 2

Global meaning in people with spinal cord injury:
content and changes

Elsbeth Littooij

Guy AM Widdershoven

Janneke M Stolwijk-Swüste

Suzan Doodeman

Carlo JW Leget

Joost Dekker

Journal of Spinal Cord Medicine, (2016) 39(2), 197-205

Abstract

Background After spinal cord injury (SCI), people are confronted with abrupt discontinuity in almost all areas of life, leading to questions on how to live a meaningful life again. Global meaning refers to basic ideas and goals that guide people in giving meaning to their lives, in specific situations. Little is known about global meaning relating to SCI and whether global meaning changes after SCI.

Purpose The purpose of this study was twofold: (i) to explore the content of global meaning of people with SCI, and (ii) to to explore whether or not global meaning changes after SCI.

Methods In-depth semi-structured interviews were conducted with 16 people with SCI. Interviews were analyzed according to the method of grounded theory.

Results (i) Five aspects of global meaning were found: core values, relationships, worldview, identity and inner posture. (ii) Overall, little change in the content of global meaning was found after SCI; specific aspects of global meaning were foregrounded after SCI.

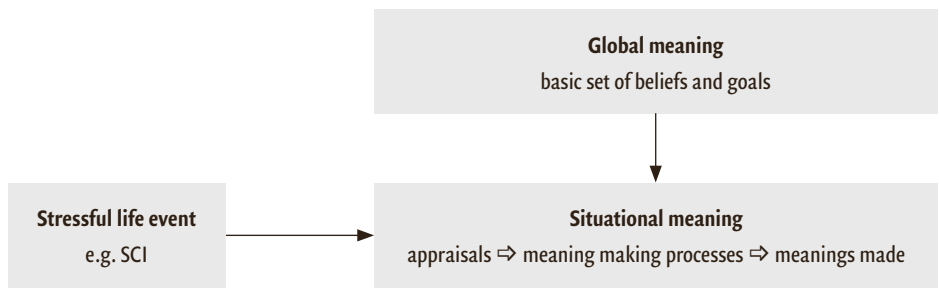
Conclusion Five aspects of global meaning were found in people with SCI. Global meaning seems hardly subject to change.

Introduction

A traumatic life event, such as spinal cord injury (SCI), constitutes a major threat to the meaning people give to their lives.[1] After SCI, people are confronted with abrupt discontinuity in almost all areas of life. Practical challenges have to be faced, together with questions on how to live a meaningful life again.[2] In the rehabilitation process, people are trained to deal with the physical, psychological, and social consequences of life with SCI.[3] In this process of adaptation and rehabilitation 'global meaning' may be a source of direction and continuity. Park has reviewed the literature regarding meaning and its effect on adjustment to stressful life events.[1,4] Park uses the term global meaning to refer to global beliefs (e.g. views regarding justice, coherence or control) and global goals (e.g. health or relationships), guiding people in living their lives. Global meaning provides individuals with cognitive frameworks, to interpret their experiences, and to motivate them in their actions. Global meaning is to be seen as the more fundamental level, and needs to be differentiated from situational meaning. Situational meaning refers to meaning in the context of a particular situation, e.g. a stressful life event like SCI. Situational meaning contains appraisals (specific beliefs about the stressful life event), which lead to meaning making processes (psychological processes aiming at giving meaning to the stressful life event), which result in meanings made (the outcome of these processes). Situational meaning is driven by a person's global meaning. This is illustrated in Fig. 1.

The concept of global meaning has been described in several terms in various disciplines.[1,4-9] Although different terms are used, there is clearly congruence among these authors on the concept of a basic set of beliefs and goals, that guides the way in which people give meaning to their lives (i.e. 'global meaning'). Psychological research on SCI focuses mainly on aspects of situational meaning or meaning making, e.g. adjustment or post traumatic growth.[10-16] Psychological research on SCI includes studies

Figure 1: *the relationship between global meaning and situational meaning*



on spirituality and purpose in life; although rarely studied, these factors have been shown to be associated with better mental health, higher quality of life and reduced mortality.[15,17,18] Although studies on spirituality or post traumatic growth in people with SCI mention aspects of global meaning, to the best of our knowledge, a more extensive exploration of the content of global meaning in people with SCI does not seem to be available. Furthermore, it is not known whether after SCI global meaning remains stable, or is subject to change. Park notes that global meaning tends to be stable after a stressful life event,[1] however, none of the studies she reviewed regard SCI. Therefore, the purpose of this study was twofold: (i) to explore the content of global meaning of people with SCI, and (ii) to explore whether or not global meaning changes after SCI.

Methods

Design

To explore the concept of global meaning, interviews were conducted with people with SCI by the first author. Subsequently, the interviews have been analyzed by the first and fourth author, using the qualitative research method of grounded theory. Interviews were held between 6–24 months after admission to the rehabilitation center. It was expected that in this phase participants would be able to reflect on their lives, their global meaning and possible changes. Presumably, they had had time to realize what had happened and to find a way to deal with their SCI, while still being able to remember how they thought and felt before they had to live with their disability. The study was approved by the accredited Medical Research Ethics Committee Slotervaart Hospital and Reade (METC-study number P1153).

Participants

Participants were recruited from clients who received treatment at Reade, center for rehabilitation and rheumatology. They had been discharged from the rehabilitation center, and were in outpatient rehabilitation. Clients with severe communication problems and psychiatric problems were excluded. Participants were purposively selected to include both men and women, younger and older clients, clients with or without a religious background, and clients with a more optimistic or a more pessimistic attitude (according to the physician in attendance). A letter was sent to potential participants, to which they could respond by returning a consent form.

Data collection

The main method of data collection was the conduct of semi-structured interviews with 16 participants, which, with permission of the participants, produced 16 audio recordings. The majority of interviews took place at participants' homes. On average interviews lasted one hour. They were conducted between August 2012 and July 2013. The interviewer minutely registered through field notes the observations she made before, during and after the interview, giving details on the broader interview situation, such as the occasional presence of a partner or friend, and nonverbal aspects of the communication. Interviews were loosely structured using a topic list, based on literature concerning global meaning. (see Appendix 1) Starting with an open question: "What has happened?" subsequent questions were: "What has changed?", and "What has not changed?" With the topic list in mind as a guideline, the interviewer followed the natural flow of the conversation. By summarizing and rephrasing what she heard, the researcher constantly tested her assumptions during the interview, getting to the deeper layers of global meaning. By asking the same question in different words, she tested if the respondent was telling about inner posture, for example. The subjects on the topic list revolved around: change and continuity, a person's values, self-image, worldview, life goals, and ideas on suffering. Based on the information revealed by interviews already administered, the topic list was continuously evaluated and adjusted. It was found, for example, that participants would say: "I am the kind of person that…" and talked about their identity. In subsequent interviews participants were asked to finish that sentence.

Data analysis

In order to analyze the data, verbatim transcriptions were made of the recorded interviews, which were then analyzed by two researchers, using the method of grounded theory.[19] Data were entered into a software program for qualitative data analysis and research, Atlas.ti (version 7.1.6, ATLAS.ti Scientific Software Development, GmbH, Berlin, Germany). The analysis was based on the transcribed interview recordings, using interviewer's impressions, reported in field notes, as background material. The actual recording was readily available through Atlas.ti, and used when listening to the tone of statements and remarks. The initial interviews were open coded in order to find aspects of global meaning, and change in global meaning. The codes found were grouped into concepts, and these concepts were gathered into larger categories, which the researchers suspected to be aspects of global meaning. When seven interviews had been conducted, transcribed and analyzed in this way, an overview was made of the aspects of global meaning found in each interview. On the basis of these overviews and categories the next interviews were analyzed, searching for these and deviant aspects of global meaning, continuity and change. When the analysis reached its saturation point at 16 interviews, five aspects of global meaning had been clearly identified from the data.

Results

Out of 29 invitations, 17 participants reacted positively, leading to 16 interviews, with one interview being cancelled due to medical reasons. 9 participants were male, 7 were female; the age ranged from 26 to 79 (Table 1). The participation of male - female respondents was 59–41%, while the whole population of newly admitted patients in the rehabilitation center in that period was 74–26%. When 13 of the 16 interviews had been conducted, the

Table 1: *Respondent characteristics*

Characteristics	Mean (range)
Age (years)	57.25 (26-79)
Time post-injury (months)	16.19 (9-24)
	No.
Sex	
Male	9
Female	7
Country of birth	
Netherlands	13
Morocco	1
Curacao	1
Egypt	1
Social status	
Single	5
Single with children	1
Married/living together with children	2
Married/living together without children	7
Living apart together*	1
Education	
Vocational training	2
High school	6
Community college	2
Undergraduate school	4
Graduate school	2
Religious background	
Christian	4
Muslim	3
Atheist	1
None	6
Other	2
Type of lesion	
Paraplegia	11
Tetraplegia	5
Completeness of lesion	
Complete	3
Incomplete	13

*married, but living in a nursing home, apart from spouse

researchers felt that a saturation point had been reached; an assumption confirmed by the fact that the last three interviews brought very little new information to light.

Aspects of global meaning

The analysis of the interviews resulted in five aspects of global meaning: core values, relationships, worldview, identity and inner posture. These aspects are all relevant, but in different persons different aspects are more prominent. Although distinguished for reasons of clear presentation, in practice the different aspects of global meaning are often interwoven. One statement can show identity, core values, relationships and inner posture at the same time. In general people do not have a conscious, well formulated, idea of their global meaning. For example, they do not have a clear set of values, that they can easily sum up. However, this does not mean that they do not have values. People's core values can be found by exploring what is important to them, or what they value in other people.

Core values

Based on the narratives of the participants and literature on global meaning,[9] we define core values as beliefs about what is right and worthwhile. Core values are self-evident, and guide behavior, and in this sense they are prescriptive. This is shown in the following example of a mother of four adult sons. It is important to her, that she does not become a nuisance now that she is disabled. In this quote she implicitly shows core values like care and responsibility for the people around her.

> *"It wouldn't help [being angry about the situation], because the boys also need to go on and pick up their lives again. And then there should not be some angry mother behind them."*
> *"I would find it terrible, to become a bother. (...) You are a bother already a little in this situation, but that I can't help. What I can do about it, however, I will certainly do." (Dutch woman, 65, married, Christian, undergraduate school, paraplegia, incomplete)*

To another respondent, the core value of 'showing interest in people' is important. This is how he finds or gives meaning, even though he is living in a nursing home as a consequence of SCI. The way he changes from 'I' to 'you' shows the self-evidence and the prescriptive element.

> *"I have a certain interest in people, yes. In (nursing home) there was a nurse, she struggled with her youngest child, with his health. Nothing serious, but it bothered her. Well, I ask… then you ask about him. 'Is everything all right?' And then you ask a second time." (Dutch man, 78, single, other religious background, high school, paraplegia, complete)*

Relationships

When asked what makes life worthwhile, participants often answer in terms of relationships with significant others. Meaningful relationships and the experience of being connected are important goals in life. Spouses, children and friends, sometimes a pet, are often mentioned as giving meaning to life, being specifically important during rehabilitation and the difficult period after SCI.

Respondent: "Yes, I go on. Or I aim to, anyway. I try." Interviewer: "Can you tell me why?" Respondent: "I have two daughters. And a wife, and a dog. And I still enjoy living." (Dutch man, 67, married, no religious background, high school, paraplegia, incomplete)

When asked what is most important in his life, now that he is paralyzed and has to spend most of his time in bed as a result of SCI, a young man answers:

"Friendship. Because friends stand by me now. So yes, that is the best investment you can do in your life, isn't it?" (Dutch man, 26, married, Muslim, high school, tetraplegia, incomplete)

Worldview

When people look for explanations for the events that happen in life, their worldview will give structure to their ideas on how these are related. Worldview becomes pre-eminently clear when people express their view on suffering and their reaction to stressful life events. Compare these completely different views for example. However much different, they all provide structure and therefore meaning.

"Does suffering have meaning? No, no, it just happens to a person. Anything can happen to anyone." (Dutch woman, 68, single, Christian, community college, tetraplegia, incomplete)

"Yes, that's what I always think: things happen for you to learn something." (Curacao woman, 61, single, Christian, high school, paraplegia, incomplete)

"I myself have always believed: Jesus has suffered for mankind, so suffering just shouldn't be necessary." (Dutch woman, 57, married, Christian, graduate school, paraplegia, complete)

A person's view on suffering influences how she deals with traumatic life events. The same goes for ideas transcending life on earth, also part of one's worldview. The last quote comes from a participant, who contracted her SCI during a shooting accident in a shopping mall. Earlier in the interview she expresses her worldview of the kingdom of God breaking through, which gives her strength to go on, after this traumatic event.

"Well, I believe. In God. And also that the shooting accident does not have the last word, but that the kingdom of God breaks through." (Dutch woman, 57, married, Christian, graduate school, paraplegia, complete)

Identity

People show a tendency to express who they are, by telling stories about themselves, about what kind of person they are. This is important to them because it structures their lives and describes their place in this world. It provides a sense of belonging, which gives meaning to their lives. At the same time it is a way of underlining their uniqueness, an expression of self-worth. When asked what has changed in his life, and if he himself has changed, after SCI, a young man answers:

"As a person I have become even more enthusiastic, even more positive. I am a party animal, so I like to chat around a little. (…) I grew up here in (big city), so I don't know anything else. So, yes, being positive, that's just part of our nature, here in the Netherlands. (…) My perseverance and my strength, that I am so strong, that is because of my childhood. Because, in my childhood, I have had my share of problems and, yes, that only makes you stronger, of course. I am a Moroccan boy, I am gay." (Moroccan man, 42, single, Muslim, high school, paraplegia, incomplete)

This quote shows several aspects of this participant's identity. He expresses personal characteristics as well as his being part of larger groups.

Another example of identity providing meaning and self-worth, is found in the following quote. This woman always was someone who wanted to know, to learn, to examine, just a little deeper than other people. This helps her to deal with her SCI as well.

"Yes, I do want to know the cause [of the SCI], I do. That is who I am. (…) I am someone, who, when I want to know something, wants to know everything. Also what is at the bottom, under the bottom, preferably. Someone else may think 'What do I care? It is written,' but I go beyond what is written." (Dutch woman, 68, single, Christian, community college, tetraplegia, incomplete)

Inner posture

When confronted with painful events in their lives, people tend to encourage themselves, or to calm themselves with prayer or meditation, or they remind themselves of what they have learned earlier in life. This helps people to bear what cannot be changed. Inner posture includes an element of acknowledgement and an element of choice and action. It involves acknowledging the facts and choosing how to relate to the facts. A good example can be found in the next quote, where the participant refers to the tragedy of losing her sister at a young age.

"Should you give meaning to something like this? I would say: don't do it. Because, my mother, I still can hear her say… She didn't know what to do with it either, of course, and she said: whom God loves, he chastises. (…) Well. I think that is horrible. Well, then you think: yes, well, I will make it without meaning and just let it happen and make the best of it." (Dutch woman, 65, married, Christian, undergraduate school, paraplegia, incomplete)

In contrast to what she had seen her mother do, when her sister died, this participant developed an inner posture of 'not giving meaning to what is meaningless' and 'making the best of it'. This is not just a philosophy of life, but it involves acting upon this philosophy. When confronted with suffering, she reminds herself and others, that this is how she sees things. This inner posture helps her to live with her SCI as well.

A young man with SCI expresses his inner posture of looking at the good things in life. He chooses to pay more attention to the good things than to the bad things:

"[People ask:] does it not gnaw at you? I say: no. No. I won't allow it to gnaw at me." (Moroccan man, 42, single, Muslim, high school, paraplegia, incomplete)

Another respondent shows his inner posture as follows:

"Now, come on, keep going. And one more time, … keep going. I just want to keep going." (Dutch man, 74, living apart together, other religious background, undergraduate school, paraplegia, incomplete)

This respondent wants to keep going. When things get difficult, he will cry, but not for too long. After a while he tells himself to 'keep going'. This inner posture influences his behavior and his actions. For example: he did all he could, to be transferred from a nursing home where people were waiting for death to come, because he could not live among people that did not want to keep going. He chooses to live in an environment that empowers his own inner posture.

Continuity and change in global meaning

In general, continuity appears to be the tendency when it comes to continuity or change in global meaning.

"In my situation, the way I know myself… (own name) is still (own name). Nothing different about that. Yes, I have a… I am (own name) with a little extra." (Moroccan man, 42, single, Muslim, high school, paraplegia, incomplete)

This respondent realizes that, as a result of his SCI, a lot has changed in his life, but he describes the changes as circumstantial. He himself, his identity, has not changed.

Even though the general tendency for global meaning is not to change, sometimes, after SCI, changes seem to occur in aspects that are part of global meaning. For example, in this respondent's identity, something seems to have changed.

"Are there things that have changed? Yes. I have always been a little bit of a loner. And of course you have to be careful with that, when something like this happens to you. You just need people much more. But also my attitude in this respect has changed. And also, I am, very strange to say, but much more… Most people talk more about themselves to me now. About their worries, their problems. Even in a way that now and then I get the feeling: I resemble the local Wailing Wall. Maybe it's because… I have more patience these days." (Dutch woman, 63, single, atheist, high school, paraplegia, complete)

This respondent reports a change in her identity in relation to others, as a consequence of her SCI. The question remains whether this is really a change in her identity, or mainly a change in the way people react to her since her SCI.

Although no fundamental changes are found, aspects of global meaning are foregrounded in confrontation with a stressful life event like SCI. People become more aware of aspects of their global meaning, when they are confronted with vulnerability, and pain, and death.

"Got many reactions. Very many visitors. In (hospital) as well as in the rehabilitation center. And that does surprise me." (Dutch man, 71, married, no religious background, undergraduate school, paraplegia, incomplete)

This respondent has become more aware of the importance of relationships with family and other people in his life. Earlier in the interview, when talking about his work, he describes himself as a person that needs to have a 'click' with other people to do business with them. Apparently relationships were always important to him, although he did not realize that at the time.

Especially inner posture becomes more prominent after SCI. When confronted with a life that has changed in many ways, people become more aware of the way they try and live with those changes. The inner posture of the woman that had been in the shooting accident, always was one of looking for boundaries and gradually trying to push them. After SCI, she becomes more aware that this is the way she always lived, but now she does it more deliberately and carefully.

Respondent: "That is how I explore the boundaries and I recognize that it is important to start close at hand. Because, when I go too far away and too far across, well… that is at the expense of things nearby. I rather push the boundaries, than that I just go overboard one or two times."
Interviewer: "And is that how you were before the shooting accident and how you operated? Or has that changed afterwards?" Respondent: "Well, I am more consciously pushing boundaries now." (Dutch woman, 57, married, Christian, graduate school, paraplegia, complete)

Discussion

The scope of our study was global meaning, a concept not extensively studied in people with SCI before. Global meaning, being the more fundamental level of meaning, has to be differentiated from situational meaning. Situational meaning and the process of meaning making are driven by a person's global meaning. This can be illustrated looking at a quote we presented in the results:

"Yes, I do want to know the cause [of the SCI], I do. That is who I am. (…) I am someone, who, when I want to know something, wants to know everything. Also what is at the bottom, under the bottom, preferably. Someone else may think 'What do I care? It is written,' but I go beyond what is written." (Dutch woman, 68, single, Christian, community college, tetraplegia, incomplete)

The situational meaning in this quote is, that the respondent wants to know everything there is to know about the cause of her SCI. This is how she finds meaning in this particular situation. This is, however, not only relevant for this situation, but part of her identity: she considers herself to be a person who wants to know, to learn, to examine, to dig deeper than other people. So she uses an element of global meaning, to explain and support the meaning making process in the specific situation.

We identified five aspects of global meaning in people with SCI: core values, relationships, worldview, identity and inner posture. The operationalizations of these aspects (Box 1) are based on the narratives of the participants, combined with the literature on global meaning.[1,4-9] Four of these aspects – core values, relationships,

worldview, identity – have been described in studies on global meaning in the broad area of stressful life events, but not specifically SCI.[1,17,18,20] Core values are global beliefs about what is right and worthwhile. They give direction to thoughts and behavior. Relationships refer to a connection between a person and others, e.g. children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are global goals in life. Worldview is a more or less coherent set of global beliefs about life, death, and suffering, that structure people's ideas on how life events are related. Identity refers to global beliefs about one's deepest self, about who, rather than what a person is. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth. The fifth aspect, inner posture, originates in Buddhism and is used in yoga and in the practice of spiritual counseling. Using a different terminology, the concept is also found in the fields of philosophy and psychotherapy: the stoics refer to inner posture as 'attitude',[21] while Frankl describes the attitude a person can choose in the face of unavoidable suffering.[6] The different aspects of global meaning are closely connected. For example, the 42 year old man with the identity of the positive, strong, Moroccan, gay boy, has an inner posture of looking at the positive side of life, and a worldview in which you get what you give. In his view, positivity and goodness are part of life: do well and get well.

Psychological research on SCI includes studies on social support,[22-25] sense of self,[18,26,27] purpose in life,[15,18,26] spiritual coping[28] and spirituality.[4,16,29,30] In studies on social support the importance of supportive relationships is widely recognized.[22-25] However, these studies focus on the role relationships play in adapting to SCI, in other words: they focus on situational meaning. Our study addresses relationships as a global goal, i.e. relationships as an aspect of global meaning. The same applies to the studies on sense of self, purpose in life and spiritual coping. Sense of self is related to our concept identity; purpose in life and spiritual coping are related to worldview; however, studies on sense of self, purpose in life or spiritual coping mainly focus on psychological adaptation to SCI, i.e. situational meaning, while our study addresses identity and worldview as aspects of global meaning. Spirituality can indeed be seen as an element of worldview, but worldview is a more comprehensive concept.

Box 1: *aspects of global meaning*

Core values	Relationships	Worldview	Identity	Inner posture
Core values are global beliefs about what is right and worthwhile. They give direction to thoughts and behavior.	Relationships refer to a connection between a person and others. Meaningful relationships and the experience of being connected are global goals in life.	Worldview is a more or less coherent set of global beliefs about life, death, and suffering, that structure people's ideas on how life events are related.	Identity refers to global beliefs about one's deepest self, about who, rather than what a person is. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth.	Inner posture helps people to bear what cannot be changed. It includes an element of acknowledgement and an element of choice and action. It involves acknowledging the facts and choosing how to relate to the facts.

We observed continuity rather than change in global meaning after SCI. This corresponds to what is found in literature on global meaning. Most researchers use the phrase 'not likely to change' or 'resistant to change', relating to (aspects of) global meaning after a traumatic event.[1,7-9,20] In our study, we also found little evidence of fundamental change: no fundamental changes in global meaning after SCI were reported. However, people did become more aware of specific aspects of their global meaning. Aspects of global meaning, which were already present prior to SCI, were foregrounded; after SCI, participants became more aware of these aspects of global meaning. This applied in particular to inner posture; people became aware of how they had dealt with difficulties in their lives prior to SCI, and used that inner posture to deal with SCI and its consequences.

It has been hypothesized that the process of adaptation to a traumatic event is guided by people's global meaning: global beliefs and goals guide the process of adaptation.[1,13,20] Given its prominence and apparent stability, it can be hypothesized that this applies also to global meaning in people with SCI: core values, relationships, worldview, identity and inner posture can be hypothesized to guide the process and outcome of rehabilitation after SCI. People with SCI seem to be aware of their global meaning, and global meaning seems to be rather stable. Therefore, global meaning may be a source of direction and continuity during the rehabilitation process after SCI. In future research, we will explore this hypothesis.

Strengths and limitations of the study

In the analysis, it was not always easy to distinguish global meaning from situational meaning. People usually do not have a clearly formulated worldview or identity, and they are not able to sum up their core values. Indicators in the data, that the level of global meaning was reached, were sudden changes of subject, emotions, silences, and metaphors. If both researchers who analyzed the interviews identified a quote as referring to global meaning, it was perceived as a strong clue that global meaning was actually referred to.

The interviews were all conducted after SCI. Obviously we were not able to interview the respondents before SCI. The interviews therefore reflect the view of the respondents in retrospect. As a result, we cannot be sure if the reported change or continuity is, at least partly, a result of retrospective bias. It is possible that people were not able to recall their past view on global meaning, or that they changed more than they remembered. However, our results show, how the respondents reflect on their current and former global meaning.

The interviews in our study took place between 6 and 24 months after onset of SCI, and we found little change in global meaning. In other studies, it was found that between 2

and 5 years changes occur in the ratings persons with SCI give to their subjective QOL.[18] Although these studies did not study global meaning, this can be an indication that after a longer period of time changes may be reported in global meaning as well.
In some interviews a spouse or a friend was present. This can be seen as both a limitation and a strength. On the one hand, the respondent may not have told everything, because they wanted to protect their spouse from certain ideas. On the other hand, the interaction between the respondent and the spouse or friend provided the interviewer with information about the relationship between the two, and sometimes the spouse stimulated the respondent, by reminding them of earlier actions or statements they themselves did not think of telling.

Conclusion

In this study, five aspects of global meaning were found. Four have been previously reported in research on global meaning, whereas inner posture has been described in other disciplines, like philosophy and spiritual counselling. In the period between 6 to 24 months after onset of SCI, global meaning appears to be relatively insensitive to change. We expect it to be a possible source of motivation and continuity in the process of rehabilitation after SCI. However, the extent to which global meaning influences the process of rehabilitation has not yet been studied. Therefore, further research is recommended to study the influence of global meaning on the process and outcome of rehabilitation.

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Conflict of interest

The authors declare no conflict of interest.

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Appendix 1

Topic list *global meaning*

1. Could you tell me what happened to you?
2. What has changed?
3. What has remained the same?
4. Do you think your SCI has a meaning or a purpose?
5. Do you think life in general has a meaning or a purpose?
6. What is really important to you in life?
7. When do you get annoyed?
8. What do you hope others will say or think about you?
9. If I ask you: 'Who are you?' what would be your answer? (Please finish the sentence: I am … someone who …)
10. Could you share some of your thoughts about death with me?
11. How do you manage to live with your SCI?
12. Has what we have discussed so far affected your rehabilitation? In what way?
13. Is there anything else you would like to say, in reaction to the interview so far?
14. How did you experience this interview?

Addendum to the data analysis section of chapter 2 (not published)

In order to analyze the data, verbatim transcriptions were made of the recorded interviews, which were then analyzed by two researchers, using the method of grounded theory. Data were entered into a software program for qualitative data analysis and research, Atlas.ti (version 7.1.6). The analysis was based on the transcribed interview recordings, using interviewer's impressions, reported in field notes, as background material. The actual recording was readily available through Atlas.ti, and used when listening to the tone of statements and remarks. The initial interviews were open coded in order to find aspects of global meaning, continuity and change. This led to the production of 260 codes.
When seven interviews had been conducted, transcribed and open coded, the 260 codes were grouped into 34 concepts of which the researchers felt they could be referring to global meaning. These were discussed with the other members of the research team. A list of the concepts can be found in box 1.

Box 1. *Concepts found in the first seven interviews*

Acceptance	Image of God
Awareness	Keep going
Bad luck	Life perspective
Badness	Life stance
Boundaries	Philosophy of life
Caution	Purpose
Changes	Putting in perspective
Concept of man	Reflecting
Control	Rehabilitation
Coping	Relationships
Death	Self-determination
Dreaming	Suffering
Ethics	Transformation
Freedom	Trust
Goodness	Upbringing
Hope	Values
Identity	Work

The concepts were gathered into larger categories, which the researchers suspected to be aspects of global meaning. On the basis of these concepts and categories the next interviews were analyzed, searching for these and deviant aspects of global meaning, continuity and change. The following interviews produced 30 more codes that could be listed under the different concepts and categories, but no new concepts arose. Taking into account the codes that the concepts were based on, and their underlying quotes, some concepts could be listed under more than one category, because they seemed to refer to more than one aspect of global meaning. For example acceptance for some respondents was a core value, whereas in other respondents it was part of or referred to their inner posture. Another example: upbringing was related to core values and a certain worldview, that respondents had inherited from their parents or wanted to pass on to their children, whereas in other respondents it was felt that their identity was formed by their upbringing. The concepts and their relation to the larger categories were discussed in the research group.

When the analysis reached its saturation point at 13 interviews, five aspects of global meaning had been clearly identified from the data. The last 3 interviews brought no new information to light. The relation of the 34 concepts and the larger categories that became the five aspects of global meaning is illustrated in Box 2.

Box 2. *Relation between the five aspects of global meaning and the 34 concepts*

Core values	*Relationships*	*Worldview*	*Identity*	*Inner posture*
Acceptance	Relationships	Bad luck	Caution	Acceptance
Caution	Self-determination	Badness	Dreaming	Awareness
Control	Trust	Boundaries	Identity	Boundaries
Ethics	Upbringing	Changes	Keep going	Coping
Freedom	Work	Concept of man	Life perspective	Dreaming
Goodness		Control	Life stance	Hope
Putting in perspective		Death	Philosophy of life	Keep going
Reflecting		Goodness	Putting in perspective	Life stance
Self-determination		Image of God	Reflecting	Purpose
Trust		Life perspective	Relationships	Putting in perspective
Upbringing		Philosophy of life	Self-determination	Rehabilitation
Values		Purpose	Trust	Reflecting
Work		Putting in perspective	Upbringing	Suffering
		Suffering	Work	Transformation
		Upbringing		Trust

Drie beuken *De natuur is niet een slagveld waarin het recht van de sterkste geldt. De natuur laat ons ultieme samenwerking zien. In het ziekenhuis werken de neurologen, logopedisten, fysiotherapeuten, ergotherapeuten en geestelijke verzorgers samen rond de patiënt, zoals deze drie stammen van de beuk met één kruin. Dit ideale beeld van samenwerking staat langs de snelweg van Utrecht naar Zeist.*

Chapter 3

The importance of *global meaning* for people rehabilitating from spinal cord injury

Elsbeth Littooij

Carlo JW Leget

Janneke M Stolwijk-Swüste

Suzan Doodeman

Guy AM Widdershoven

Joost Dekker

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Abstract

Study design Qualitative study.

Objectives To explore whether aspects of global meaning (that is, fundamental beliefs and life goals concerning core values, relationships, worldview, identity and inner posture) are associated with processes and outcomes in rehabilitation, as experienced by people with spinal cord injury (SCI).

Setting People living in the community receiving outpatient rehabilitation in a Dutch rehabilitation center.

Methods In-depth semi-structured interviews were conducted with 16 people with SCI. Interviews were analyzed using qualitative research methods: structural and provisional coding.

Results Core values, relationships, worldview, identity and inner posture (that is, the way in which people relate to the facts of life) were associated with various processes and outcomes of rehabilitation. Elements of the rehabilitation process included motivation, regulation of emotion, making decisions and handling stress. Elements of the outcome of rehabilitation included physical functioning, emotional functioning, social functioning and subjective sense of meaning. The influence was positive, with the exception of one case in which worldview and inner posture were negatively associated with motivation. Besides that, respondents emphasized the importance of rehabilitation professionals attuning to their global meaning.

Conclusion All aspects of global meaning were positively associated with various processes and outcomes of rehabilitation. It is recommended that rehabilitation professionals are aware of the importance of global meaning to people with SCI and that they take people's fundamental beliefs and life goals into account.

Introduction

Global meaning has been hypothesized to guide the process of adaptation to a traumatic event, such as spinal cord injury (SCI).[1-3] The term 'global meaning' refers to fundamental beliefs and life goals that guide people in living their lives, help them interpret their experiences and motivate them in their actions. In a previous study, we explored the content of global meaning in people with SCI. We found that global meaning in people with SCI comprises five interlinked, yet distinguishable aspects, that is, core values, relationships, worldview, identity and inner posture.[4] *Core values* are fundamental beliefs about what is right and worthwhile. They give direction to thoughts and behavior. *Relationships* refers to a connection between a person and others, for example, children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are important goals in life. *Worldview* is a more or less coherent set of beliefs about life, death, and suffering, that structure people's ideas on how life events are related. *Identity* refers to fundamental beliefs about one's deepest self. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth. *Inner posture* helps people bear what cannot be changed, which is an important goal in life. Inner posture includes an element of acknowledgement and an element of action. It involves acknowledging the facts of life and relating to them. Global meaning can be considered as the more fundamental level and needs to be differentiated from situational meaning. Situational meaning refers to specific beliefs about the traumatic event (appraisals), psychological processes aiming at reduction of distress ('meaning making'), and the outcome of these processes ('meanings made').[2,3]

In SCI research, psychological factors have been shown to be associated with indicators of adjustment to SCI, such as well-being, mental health, and quality of life.[5-9] Psychological studies mostly focus on psychological processes, that is, situational meaning. Few studies have examined the role of global meaning in the process of adaptation to SCI. Supportive relationships have been identified as resources in adapting to SCI.[10-14] Spirituality, which is a part of *worldview*, has been found to influence adaptation to SCI.[10,15] These findings provide some support for the hypothesis that global meaning guides the process of adaptation to SCI. A comprehensive exploration of the role of fundamental beliefs and life goals in the adaptation to SCI (or other groups of people with disabilities) does not seem to be available.

On the basis of the general hypothesis that global meaning guides the process of adaptation to a traumatic event,[1-4] we explored whether people with SCI associated their global meaning with their rehabilitation, and if so with what elements of the various processes and outcomes of rehabilitation. Hence, the purpose of this study was to explore whether global meaning is associated with processes and outcomes of rehabilitation, as experienced by people with SCI.

Materials and methods

Design

Interviews were conducted with people with SCI by the first author 6-24 months after the participant was admitted to the rehabilitation center. The study was approved by the accredited Medical Research Ethics Committee Slotervaart Hospital and Reade (METC-study number P1153).

Participants

Participants were recruited from clients who had been discharged from Reade (center for rehabilitation) and were in outpatient rehabilitation. Clients with severe communication problems and psychiatric problems were excluded. Participants were purposively selected to include both men and women, younger and older clients, clients with or without a religious background, and clients with a more optimistic or a more pessimistic attitude (according to the physician in attendance). A letter was sent to potential participants, to which they could respond by returning a consent form.

Data collection

Between August 2012 and July 2013 the first author conducted semi-structured interviews with 16 participants, which resulted in 16 audio-recordings, with permission of the participants. The majority of interviews took place at the participants' homes. On average interviews lasted 1 h, the longest lasting 1 h and 38 min and the shortest lasting 24 min. The interviewer wrote down in field notes the observations she made before, during and after the interview, giving details of the broader interview situation, such as the occasional presence of a partner or friend, a radio playing religious songs, and non-verbal aspects of the communication.

Interviews were loosely structured using a topic list, based on literature concerning global meaning.[4] (see Appendix 1) Part of the questions evolved around the rehabilitation process and whether the respondents thought that their global meaning affected the process and outcome of their rehabilitation. The interviewer did not use these exact words, but she would summarize the conversation so far and then ask for the influence on process and outcome of rehabilitation.

Data analysis

Verbatim transcriptions were made of the recorded interviews, which were then analyzed by two researchers (EL and SD), using structural and provisional coding.[16] In the structural coding phase, the researchers structured the interviews in line with the research question about the relationship between global meaning and rehabilitation, and identified quotes about processes and outcomes of rehabilitation. These quotes were then analyzed provisionally, using aspects of global meaning and determinants of process and outcome of rehabilitation as codes, to determine in what way global meaning affects the process and outcome of rehabilitation. During the interviews and at the beginning of the analysis, we did not have specific variables of process and outcome in mind. This is in line with the exploratory nature of qualitative research. We did not ask our respondents for specific components of the International Classification of Functioning, Disability and Health (ICF) or specific dimensions of quality of life; we used the generic term rehabilitation and analyzed afterwards which domains of rehabilitation were mentioned by the respondents. During the analysis we structured the quotes regarding rehabilitation using the ICF[17] and rehabilitation literature. In that process we found that the ICF provided descriptions for the quotes regarding processes and that the quotes regarding outcomes were best described using quality of life terminology.[18,19] The processes and outcomes we found are presented in the results section in Box 1: rehabilitation processes, and Box 2: outcomes of rehabilitation.

Data were entered into a software program for qualitative data analysis and research, Atlas.ti (version 7.1.8). The analysis was based on the transcribed interview recordings, using interviewer's impressions, reported in field notes, as background material. The actual recording was readily available through Atlas.ti, and used to listen to the tone of statements and remarks. The analysis reached a saturation point at 13 interviews, after which 3 more interviews were conducted that added no new information.

Results

Out of 29 invitations, 17 participants sent back the consent form, leading to 16 interviews; 1 interview was cancelled because of medical reasons. Nine participants were male and seven were female; the age ranged from 26 to 79 years (Table 1). Two respondents were living in a nursing home, the other fourteen were living in the community.

All five aspects of global meaning (that is, core values, relationships, worldview, identity and inner posture) were found to affect various processes and outcomes of rehabilitation in people with SCI. Elements of the rehabilitation process that were affected by global meaning were motivation, regulation of emotion, making decisions, and handling stress (see Box 1 for details). Rehabilitation outcomes affected by global meaning were physical functioning, emotional functioning, social functioning, and subjective sense of meaning (see Box 2 for details).

The relationship between aspects of global meaning and elements of process and outcome varied between respondents. However, over all respondents, all five aspects of global meaning were found to affect the various elements of process and outcome.

Influence of global meaning on rehabilitation processes

Motivation

All aspects of global meaning were perceived to affect motivation in people with SCI. According to one respondent relationships affected his motivation to rehabilitate:

"Life has a meaning, yes. In relation to other people, my wife for example. (...) I believe I still

Table 1: *Respondent characteristics*

Characteristics	Mean (range)
Age (years)	57.25 (26-79)
Time post-injury (months)	16.19 (9-24)
	No.
Sex	
Male	9
Female	7
Country of birth	
Netherlands	13
Morocco	1
Curacao	1
Egypt	1
Social status	
Single	5
Single with children	1
Married/living together with children	2
Married/living together without children	7
Living apart together*	1
Education	
Vocational training	2
High school	6
Community college	2
Undergraduate school	4
Graduate school	2
Religious background	
Christian	4
Muslim	3
Atheist	1
None	6
Other	2
Type of lesion	
Paraplegia	11
Tetraplegia	5
Completeness of lesion	
Complete	3
Incomplete	13

*married, but living in a nursing home, apart from spouse

have value for other people. If you don't, you can just as well end it right away. (...) That has given me motivation during my rehabilitation. I want to be able to really contribute something again." (man, 59)

One respondent explicitly stated that his core values and his worldview gave him focus to rehabilitate. According to his worldview, positivism and kindness are part of life, and this motivated him to stay focused in the process of rehabilitation:

"Positivism, kindness, (...) that fortunately still exists in the world. (…) I strongly believe that when you do good, you will be treated well. When you do bad things, you get bad things back. (…) I just say, like…, come on, bring it on. I'll just see what comes my way. And er…, that provides focus to rehabilitate." (man, 42)

For another respondent, global meaning was counterproductive to the rehabilitation process. His identity as a laid-back person, together with his worldview that everything just happens and you cannot influence it, and his inner posture of letting things come as they come, affected his motivation to rehabilitate in a negative way:

"I always was a down-to-earth person, easy-going. I was contented. I still am. (...) What shall I say, it is fate. Everybody gets his fate. You cannot get around that. (…) I can't practice. I just can't." (man, 67)

Box 1: *Rehabilitation processes (as described in the ICF[17])*

Motivation	Regulation of emotion	Making decisions	Handling stress
Mental functions that produce the incentive to act; the conscious or unconscious driving force for action.	Mental functions that control the experience and display of affect.	Making a choice among options, implementing the choice, and evaluating the effects of the choice.	Carrying out simple or complex and coordinated actions to cope with pressure, emergencies or stress.

Box 2: *outcomes of rehabilitation (based on quality of life literature[18,19])*

Physical functioning	Emotional functioning	Social functioning	Subjective sense of meaning
The ability to perform self-care activities (for example, eating, bathing, dressing), mobility and more strenuous physical activities.	Experiencing and acting on feelings of well-being or distress.	Maintaining social contacts and other activities (for example, visits with friends and relatives), and social ties or resources (for example, close friends and relatives who can be relied upon for tangible and intangible support).	The experience that life is meaningful or has a purpose and is worth living.

Regulation of emotion

Identity, worldview, inner posture, relationships and core values were perceived to affect the regulation of emotion. One respondent's identity as a strong, religious woman, helped her direct her energy to the rehabilitation process, and not waste it on crying. She thought it was all right to cry sometimes, but she did not want it to consume all her energy:

"Respondent: And then I told myself: 'you are not going to cry today'. (…)
Interviewer: Why not cry?
Respondent: Because it is a sign of weakness. And I am strong, am I not? I was the one capable of anything. I always said… I am religious too, you know. And I thought: what God has meant for me, bring it on, I can handle it. You know, like that. (…) I did not want to cry all the time." (woman, 59)

Another respondent's worldview helped him to regulate his emotions when things got difficult. His worldview was that life is circular: everything goes on, back to the source, and then it starts again. This, combined with his inner posture of 'wanting to go on', got him back on track when he got overwhelmed:

"When we are sad, when things are heavy, my wife and I cry together, but then I say: 'stop, I have to go on'. And then I go on again. You just have to go on. (…) Everything goes on. Back to the source. And then it starts again. (…) One would be stupid to not go on, wouldn't one? Of course you go on, you just do." (man, 74)

Making decisions

Global meaning was found to affect the way in which people make decisions, as well as the content of the decisions. In the above-mentioned respondent, his worldview and inner posture of 'going on' helped him to make the decision to do all he could, to be transferred out of a nursing home where, in his view, people were waiting for death to come. He could not live among people that did not want to keep going. He was transferred to another nursing home, where he was stimulated every day to exercise and to try and make progress. He chose to live in an environment that was in line with his worldview and his inner posture:

"Go on. That's the only thing, that's what I want, yes. (...) Well, it was a problem, for those people, every day, they were just waiting to go to sleep, and eventually die. They just wanted to die. They didn't want to go on, but they had to. I thought that was terrible. (...) Here it is different. I like it here; this is much better. I had to do it, to move here." (man, 74)

For another respondent, her core values, identity, inner posture, and worldview influenced the decisions she made concerning her rehabilitation. Her core value of being useful, her identity as a pastor, and her inner posture of carefully prioritizing and choosing how to spend her energy, increased the pace of her rehabilitation. Part of her worldview was that Jesus suffered for mankind; hence, suffering should not be necessary. She avoided what she saw as unnecessary suffering by not doing heavy physical exercises. This brought her in conflict with some of the therapists, but it also helped her to hold on and to accomplish her goals in her own way:

"I have become very dependent and now I try to be more independent, and not let myself be restricted too much by the physical aspects. But take up the other parts first: being useful in society, in church. By picking up those things and giving them priority, actually, the whole process of rehabilitation has gained momentum. But in (the rehabilitation center) they regularly told me that I could accomplish more. (...) Some therapists got the wrong impression that physical rehabilitation wasn't important to me. (…) On the one hand I like to bend things to my own will, and on the other hand I just go with the flow. (…) That is how I explore the boundaries and I recognize, that it is important to start close at hand." (woman, 57)

Handling stress

All aspects of global meaning were found to be helpful in handling stress and other psychological demands. A 42-year old man with SCI chose to pay more attention to the good things than to the bad things in life. This inner posture, along with his core values of commitment and being the best person you can be, and his identity of a positive, active person helped him when he was tired or frustrated or when he felt sad. This provided him with a source of energy to handle the stress of living with SCI:

"[In two years, after rehabilitation,] which boss is waiting for me, 44 years old and having SCI? No, I can forget that. (…) [People ask:] does it not gnaw at you? I say: no. No. I won't allow it to gnaw at me. (…) I know that I am a strong person. I know that I am sporty. I have perseverance." (man, 42)

Influence of global meaning on outcomes of rehabilitation

Physical functioning

Several respondents reported an influence of global meaning on their physical functioning. One respondent's worldview that God gives her strength, affected her ability to walk again, she reported:

"Interviewer: has your life stance affected your rehabilitation process and your current functioning?
Respondent: yes, of course, that is logical. (...) it has to do with my faith. I have a strong faith. That definitely helps. (...) People say: 'six months ago you could do nothing, and now you are walking again'. (...) That is strength. And my strength comes from my faith." (woman, 68)

Another woman's worldview that all people can grow, and her identity of a strong woman, along with her positive inner posture of keeping on trying and fighting, affected her ability to shower and brush her teeth while standing:

"People can grow; I think everybody can. (...) You can feel how you grow inside. It is difficult

to explain, but, you know, in the beginning I had to sit while showering, sit while brushing my teeth, that did cost a lot of strength. For you need strength you know, when you brush your teeth at the sink. Now I shower standing up, I brush my teeth standing up. (...) I always keep fighting, I keep my strength." (woman, 61)

Emotional functioning

All aspects of global meaning were found to affect emotional functioning. In one respondent her inner posture of 'letting things come as they come and working hard', along with her core values of harmony and reliability, and the global goal of the relationships with her sons, affected her emotional functioning:

"Angry, no. I don't get angry. That is energy for nothing. (...) It wouldn't help, because the boys also need to go on and pick up their lives again. And then there should not be some angry mother behind them." (woman, 65)

A 78-year old man, with core values of humor and being interested in others, regarded the relationships in the rehabilitation center as an important factor in his emotional rehabilitation. Hereby he implied that relationships were important for his emotional functioning:

"My life has a meaning, even now. For my children, my friends, my girlfriend. They are happy with me, and I am happy with them. (...) When you are emotionally struggling and they can help you with that, that is important in rehabilitation too [besides the physical aspects]. For example, they forced me to eat in the common dining room. Then you are in a community, you start to talk with people. That is important. To live together, with other people. Not keeping yourself apart. Showing an interest in others." (man, 78)

Social functioning

Inner posture, identity, core values, relationships, and worldview were found to affect social functioning. One of the above-mentioned respondents, the woman with the identity of being a pastor, the core value of being useful in society and her worldview of the kingdom of God breaking through, took up her responsibilities in society as soon as she could. During her in-patient rehabilitation, she tentatively took up her profession again by taking care of the sermon in a Christmas service in the rehabilitation center. In a memorial service for the shooting incident, as a result of which she got her SCI, she had an essential contribution, which meant a lot to many people and to herself:

" Well, I believe. In God. And also that the shooting accident does not have the last word, but that the kingdom of God breaks through. (...) Easter Monday was the memorial service and I was able to say something there too. (...) And that afternoon I could attend the prayer-service. (…) I am taking up my preaching again. That is one of the first things that has been taken up, actually." (woman, 57)

A respondent who as a result of his SCI was not able to work at the time of the interview, chose to regard his rehabilitation as if it were his work. This allowed him to participate

in society in a meaningful way. His inner posture of paying more attention to the good things than to the bad things in life, and his identity of a positive, active person, helped him do so:

"I think of it [rehabilitation], as my work now. Now I work on my health, my senses, my emotions, my personal things. And then I go to (the rehabilitation center) three days, the whole year, to exercise. (…) You go out to go to work, I go out to go work on my health. I was working on my future before, and I still am. Only the goal is different." (man, 42)

Subjective sense of meaning

All aspects of global meaning provided participants with a subjective sense of meaning. They experienced their lives as meaningful, despite, or sometimes as a result of, the changes due to their SCI.

A 63-year old woman, who previously suffered from depression and felt lonely, now enjoys contact with people around her, like friends, or strangers in the street, or the people who help her with her daily care. Relationships, being part of her global meaning, had always been important to her, but previously it was a struggle to maintain meaningful relationships. After SCI, as she reported, her inhibitions decreased. Her SCI had been a catalyst in this process. The possibility to shape her relationships and her core values of being interested in people and being helpful to another person, gave her life a new meaning:

"In general, my life hasn't gotten worse. Of course there are many disadvantages, and it isn't nice, not being able to go to bed by yourself, I mean… and being dragged along, but that is only now and then. And moreover, I have become closer to my friends. (…) Most people talk more about themselves to me now. About their worries, their problems. Even in a way that now and then I get the feeling: I resemble the local Wailing Wall." (woman, 63)

In one of the above-mentioned respondents, his global meaning affected his motivation to rehabilitate in a negative way, however, it also provided him with a subjective sense of meaning, which made it easier to live with his SCI:

"Respondent: It is fate. I don't blame anyone. Not anyone else, not myself. (…) When I die tomorrow, well, I think… it would be sad for my wife, but, yes, I have had a good life. I have done everything that I wanted to do and have got everything I want to have. (…) I am a contented person.
Wife: He is rather cool about it. He may be a bit lazy, but perhaps that's a good thing. Makes it bearable." (man, 67)

Discussion and Conclusion

Discussion

In this study we found that aspects of global meaning (that is, core values, relationships, worldview, identity and inner posture) were associated with various processes and

outcomes of rehabilitation in people with SCI. Our respondents reported about the following elements of the rehabilitation process: motivation, regulation of emotion, making decisions, and handling stress; and the rehabilitation outcomes: physical functioning, emotional functioning, social functioning and subjective sense of meaning

Global meaning and processes and outcomes of rehabilitation

Associations for global meaning with various processes and outcomes of rehabilitation augment the current literature, which mostly focuses on the impact of situational goals, beliefs and processes. For example, in literature, the importance of supportive relationships in the adaption to SCI is widely recognized. Social support from family and friends, peer mentoring and support from professionals have been found to be resources for emotional adjustment and motivation.[10, 20,21] However, these studies focus on the processes in relationships which affect adaptation to SCI. Our study addresses the impact of relationships as a life goal. Our respondents reported about relationships as an aspect of global meaning to influence elements of the rehabilitation process such as motivation, regulation of emotion, making decisions and handling stress and outcomes like physical, emotional and social functioning as well as a subjective sense of meaning. Global meaning has been hypothesized to guide the process of adaptation to SCI.[1-4] Therefore, relationships as an aspect of global meaning (viz. a life goal) may guide the psychological processes through which social support affects adaptation to SCI. More research is needed to study the mechanisms behind this.

The same applies to coping. In current literature on adjustment to SCI, coping is an important factor.[8, 9, 21,22] Coping can be seen as related to the concept of inner posture. However, coping strategies are applied in a specific situation,[23] whereas inner posture refers to the way people deal with life events in general. Inner posture, being part of global meaning, may drive coping processes, which are part of situational meaning.

Studies on spirituality of people with SCI focus mainly on spiritual or religious coping,[24] or on the question whether spirituality grows or decreases after SCI.[25] In general, spirituality is found to influence general health, and to provide motivation in life.[3] Some state that spirituality influences adaptation to living with SCI,[15] or gives strength to continue with life.[10] The present study provides a broader perspective: not only spirituality, but also other aspects of worldview, for example, the thought that life is circular or that everything just happens and one cannot do much about it, influence the rehabilitation process.

Respondents reported about the influence of global meaning on the outcome of rehabilitation in terms of physical, emotional and social functioning. Besides that, they indicated that they experienced their lives as meaningful, despite, or sometimes as a result of, the changes due to their SCI. This subjective sense of meaning appeared to be an important outcome of rehabilitation to them.

For the most part, participants felt that their global meaning positively affected processes and outcomes of their rehabilitation. However, in one case several aspects of global meaning were counterproductive to an element of the rehabilitation process. In

this particular case, the respondent's laid-back identity, his worldview that things just happen and one cannot do much about it, and his inner posture of letting things come as they come had a negative influence on the motivation to practice.

Besides that, global meaning can sometimes cause conflict with rehabilitation professionals when they do not respond to it, or do not recognize it as valuable and helpful. The response of professionals, or the lack of it, to the global meaning of people with SCI can affect, for example, a person's motivation. One respondent's core values affected her motivation to rehabilitate. Her core values of respect, valuing people and treating each other with warmth, were met in one rehabilitation center and not in another. She related this to her ability to open up and fully engage in the rehabilitation process. In the first rehabilitation center the rehabilitation professionals addressed her core values. This motivated her to actively engage in the rehabilitation program. She felt that later on her rehabilitation was not showing any progress, which she regarded as a consequence of the fact that her core values were not met in the second rehabilitation center.

Methodological considerations

In this qualitative study, we assessed how people experience the role of global meaning in rehabilitation. It clearly shows that, according to people with SCI, global meaning is important in several processes and outcomes of their rehabilitation. All respondents reported an influence of global meaning on processes and outcomes of rehabilitation. However, the sample size was small and selection bias cannot be excluded: the respondents may have had a prior interest in global meaning. We do not have information from the people who refused to take part in the study.

This qualitative study generated hypotheses on the role of global meaning in rehabilitation. Future research is needed to empirically test whether global meaning is associated with these and perhaps other processes and outcomes of rehabilitation.

In some interviews a spouse or a friend was present. This can be seen as both a limitation and a strength. The respondent may not have told everything, because they wanted to protect their spouse from certain ideas. Yet, the interaction between the respondent and the spouse or friend provided the interviewer with information that would otherwise be unavailable (for example: the friend of one of the respondents reminded him of his belief in miracles, which led to the respondent telling about the importance of his faith in his rehabilitation).

Conclusion

All aspects of global meaning, that is, core values, relationships, worldview, identity and inner posture were positively associated with various processes and outcomes of rehabilitation; the elements of the rehabilitation process included motivation, regulation of emotion, making decisions, and handling stress; the outcome elements included physical functioning, emotional functioning, social functioning, and subjective sense of meaning. It is recommended that rehabilitation professionals are aware of the importance of global meaning to people with SCI and that they take people's global meaning into account.

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Conflict of interest

The authors declare no conflict of interest.

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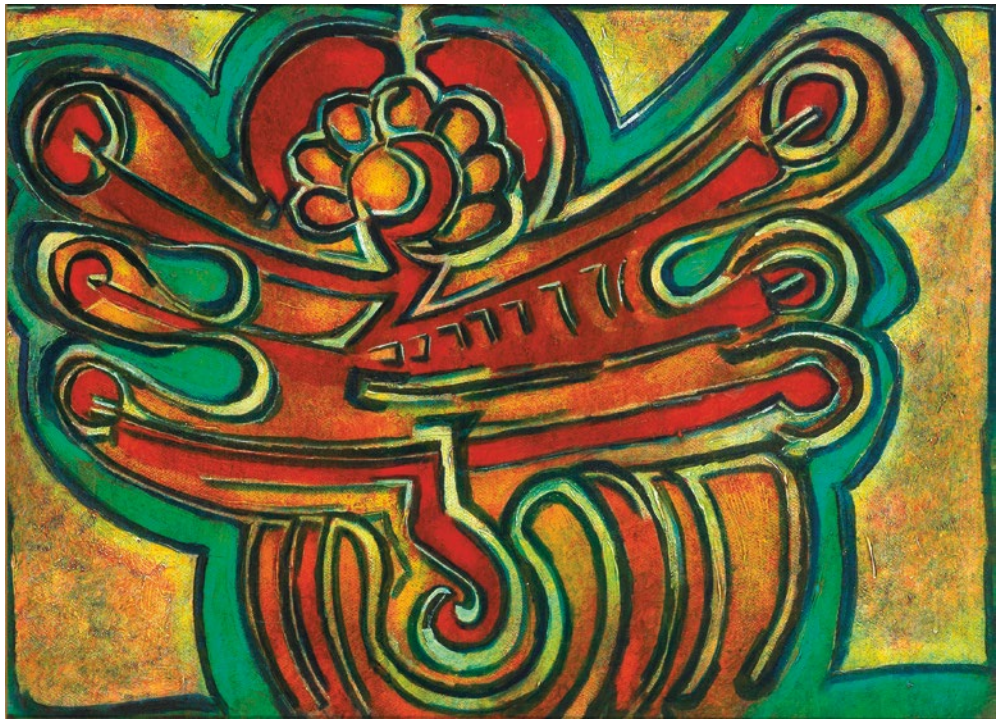
Appendix 1

Topic list *global meaning*

1. Could you tell me what happened to you?
2. What has changed?
3. What has remained the same?
4. Do you think your SCI has a meaning or a purpose?
5. Do you think life in general has a meaning or a purpose?
6. What is really important to you in life?
7. When do you get annoyed?
8. What do you hope others will say or think about you?
9. If I ask you: 'Who are you?' what would be your answer? (Please finish the sentence: I am … someone who …)
10. Could you share some of your thoughts about death with me?
11. How do you manage to live with your SCI?
12. Has what we have discussed so far affected your rehabilitation? In what way?
13. Is there anything else you would like to say, in reaction to the interview so far?
14. How did you experience this interview?



'Kom maar op grasmaaier' zo spreekt het madeliefje *Om een beeld te schetsen hoe ik dacht de hele wereld aan te kunnen heb ik dit schilderij van het moedige madeliefje gemaakt. Zo mijn hoofd eraf en zo de volgende dag een nieuw hoofd erbij! Het schilderij laat mijn vrolijke optimisme zien. Ik wist twintig jaar geleden nog niet dat een beroerte zo moe maakt en de somberheid op de loer ligt. Zelf ben ik niet somber, maar alle dagen vrolijk. Ik ben zo vrolijk als het madeliefje. Zoiets heeft niets te maken met de twee hersenhelften. Maar gewoon met mijn geestelijke instelling: de vrolijkheid geloof ik en de somberte geloof ik niet.*

Chapter 4

Global meaning in people with stroke: *content and changes*

Elsbeth Littooij

Joost Dekker

Judith Vloothuis

Carlo JW Leget

Guy AM Widdershoven

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Abstract

After a traumatic event like a stroke, people need to find meaning and control again. This study enhances knowledge on one of the driving principles behind meaning making processes: global meaning. Global meaning refers to individuals' general orienting systems, comprising fundamental beliefs and life goals. Little is known about global meaning in people with stroke and whether global meaning changes after stroke. In this qualitative study, five aspects of global meaning were found: core values, relationships, worldview, identity and inner posture. Continuity in all aspects was reported, but worldview, identity and inner posture were also subject to change.

Introduction

Living with a stroke has a strong impact on people's lives. It can result in different combinations of physical, cognitive, emotional and behavioral problems, which have implications for all areas of life including practical, social and vocational aspects.[1-3] Among the most reported effects are the experience of identity changes and social isolation.[1,4-6] After a traumatic life event such as stroke people need to find meaning and control again.[7-9] Finding meaning is positively associated with adaptation[8,10] and quality of life or well-being in people with stroke.[2]

The term 'global meaning' was first used by Park and Folkman in their meaning making model.[11] Global meaning refers to individuals' general orienting systems, comprising fundamental beliefs and life goals. Global meaning provides individuals with cognitive frameworks to interpret their experiences and to motivate them in their actions. Global meaning is to be seen as the more fundamental level of meaning and has to be differentiated from meaning making. Meaning making refers to psychological processes of finding meaning in the context of a particular situation, e.g. a stressful life event like a stroke.[7] The concept of global meaning has been described in several terms in various disciplines.[7,12-18] Although different terms are used there is clearly congruence among these authors on the concept of a basic set of beliefs and goals that guide the way in which people give meaning to their lives (i.e. 'global meaning').

This study is part of a larger project regarding global meaning in the context of traumatic life events such as spinal cord injury or a stroke. After spinal cord injury or stroke, people need to regain strength and to learn to live with the consequences of their injury. Global meaning has been hypothesized to guide the process of adaptation to a traumatic event.[7,12,19] Prior to the present study we studied global meaning in people with spinal cord injury[18] and the perceived influence on processes and outcomes of rehabilitation.[20] In that study we found five aspects of global meaning, namely, core values, relationships, worldview, identity and inner posture. *Core values* are fundamental beliefs about what is right and worthwhile. They give direction to thoughts and behavior. *Relationships* refer to a connection between a person and others, for example, children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are life goals. *Worldview* is a more or less coherent set of beliefs about life, death, and suffering, that structure people's ideas on how life events are related. *Identity* refers to fundamental beliefs about one's deepest self. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth. *Inner posture* helps people to bear what cannot be changed, which is an important goal in life. Inner posture includes an element of acknowledgement and an element of action. It involves acknowledging the facts of life and relating to them. Four of these five aspects (core values, relationships, worldview, identity) are found in literature on stressful life events.[4,15,17,21] The term *inner posture* was coined by us in this research project in order to indicate a dimension not found in previous research.

Besides that, we studied whether people with spinal cord injury experienced change in their global meaning. Overall, respondents reported little change in the content of global meaning after spinal cord injury. However, specific aspects of global meaning were foregrounded.[18]

In this study, we focus on global meaning in people with stroke. Psychological research on stroke does address meaning, but not global meaning. It addresses giving or finding meaning either as a coping mechanism,[8,10,22] or as an engagement in meaningful activities.[2,3,9](Davis et al., 2013;Kessler et al., 2009;Rochette et al., 2007) Park has reviewed the literature regarding meaning and its effect on adjustment to stressful life events.[7,12] She notes that global meaning tends to be stable after a stressful life event,[7] a tendency we also found in our study on global meaning in people with spinal cord injury.[18] However, given the cognitive consequences of a stroke, the question arises how these consequences may affect the stability of global meaning after stroke. Only one of the studies Park reviewed regards stroke,[23] and that study focuses on cognitive processing and post traumatic growth after stroke, and not on global meaning. To the best of our knowledge, an extensive exploration of global meaning (i.e. fundamental beliefs and life goals), and its stability, in people with stroke is not available. Therefore, the purpose of this study was twofold: (i) to explore global meaning in people with stroke and (ii) to explore whether or not global meaning changes after stroke.

Methods

Design

Semi-structured interviews were conducted with people with stroke by the first author (EL), who is an experienced spiritual counsellor. Interviews were held between 4 and 26 months after admission to the rehabilitation center. A letter was sent to potential participants to which they could respond by returning a consent form. Besides that, people who spontaneously applied for participation in the study, because they heard about it from other participants, were also included if they met the inclusion criteria. In the invitation letter supplementary counselling was offered, if participants wanted to further reflect on the subjects raised in the interview. One participant made use of this option. The study was approved by the accredited Medical Research Ethics Committee Slotervaart Hospital and Reade (METC-study number P1153).

Recruitment

Participants were recruited from clients with a first stroke, who received outpatient treatment at Reade, center for rehabilitation and rheumatology. Participants were purposefully selected to include both men and women and people with a more optimistic and a more pessimistic attitude, according to the physician assistant in attendance. Inclusion criteria were as follows: being in outpatient rehabilitation, adapting to living in the community with a stroke, and being able to engage in a conversation. Clients with severe communication problems were excluded. Approximately half of the respondents were familiar with the two spiritual counselors in the rehabilitation center, of which the first author is one. Her colleague did not take part in the study. The relationships between researcher and participants varied from an intensive counseling relationship, via knowing that spiritual counseling was available, to not knowing her at all.

Data collection

The main method of data collection consisted of semi-structured interviews with 16 participants which, with permission of the participants, resulted in 16 audio-recordings. The majority of interviews took place at the participants' homes. On average interviews lasted 69 minutes. They were conducted between October 2013 and July 2014. The interviewer wrote down in field notes observations she made before, during and after the interview, giving details that could not always be heard on tape, such as the radio playing religious songs, the occasional presence of a partner or friend, and nonverbal aspects of the communication.

Interviews were loosely structured using a topic list based on literature concerning global meaning.[14-17,24] (see Appendix 1) The subjects on the topic list revolved around change and continuity, a person's values, self-image, worldview, life goals, and ideas on suffering. Starting with an open question: "What has happened?" subsequent questions were: "What has changed?", and "What has not changed?". With the topic list in mind as a guideline, the interviewer followed the natural flow of the conversation. By summarizing and rephrasing what she heard, the researcher constantly tested her assumptions during the interview, getting to the deeper layers of global meaning. By asking the same question in different words, she tested if the respondent was expressing his worldview, for example.

Data analysis

In order to analyze the data verbatim transcripts were made of the recorded interviews, which were then analyzed by two researchers using the method of grounded theory.[25] Data were entered into a software program for qualitative data analysis and research, Atlas.ti (version 7.1.6). The analysis was based on the transcribed interview recordings, using the interviewer's impressions, reported in field notes, as background material. The actual recording was readily available through Atlas.ti, and was used for listening to the tone of statements and remarks. Although previous research on people with spinal cord injury had already shaped ideas about global meaning,[18] the researchers who analyzed the interviews were especially focused on the possibility that the interviews with people with stroke might provide different outcomes. They regularly discussed their findings with the other researchers, in order to stay as open-minded as possible. In grounded theory, a theory is developed during the process of interviewing and analyzing, constantly testing assumptions and gradually adapting ideas. Therefore, in order to be as open as possible, the researchers started the analysis by 'open coding' the transcripts of the interviews, while keeping close to the text, to allow for the possibility that different aspects of global meaning might be found in people with stroke, as compared to people

Table 1: *Respondent characteristics*

Characteristics	Mean (range)
Age (years)	59.25 (42-77)
Time post-injury (months)	13.31 (4-26)
	No.
Sex	
Male	11
Female	5
Country of birth	
Netherlands	13
Suriname	2
Curacao	1
Social status	
Single	6
Single with children	1
Married/living together with children	1
Married/living together without children	7
Living apart together	1
Education	
Vocational training	4
High school	3
Community college	2
Undergraduate school	2
Graduate school	5
Religious background	
Christian	4
Atheist	2
Humanist	1
None	9

with spinal cord injury. The codes were grouped into concepts and these concepts were gathered into larger categories, which the researchers assumed to be aspects of global meaning. When eight interviews had been conducted, transcribed and analyzed in this way, an overview was made of the aspects of global meaning found in each interview. On the basis of these overviews and categories the next interviews were analyzed searching for these and different aspects of global meaning, continuity and change.

Results

Out of 27 invitation letters and 4 spontaneous applications, 16 people reacted positively. 11 of them were male, 5 were female. Their age ranged from 42 to 77. (see Table 1) One respondent was living in a nursing home, the other 15 in the community. For various reasons 3 of the interviews took place at the rehabilitation center, the other 13 at the respondents' homes. After 12 interviews the researchers felt that saturation was reached, which was confirmed by the fact that the last four interviews produced no new information.

Aspects of global meaning

Five aspects of global meaning emerged from the analysis of the interviews: core values, relationships, worldview, identity and inner posture. Although distinguished for reasons of clear presentation, in practice the different aspects of global meaning were often interwoven. All aspects of global meaning were found in all respondents, however, respondents were not equally aware of their global meaning. Besides that, they differed in their ability to reflect on their global meaning.

Core values

Based on the narratives of the participants and literature on global meaning[17] we define core values as fundamental beliefs about what is right and worthwhile and life goals worthy to be pursued. Core values are self-evident, and guide behavior and in this sense they are prescriptive. One respondent referred to core values such as faithfulness and being trustworthy in the following quote:

> *"Participating in volunteer work is not without obligations. (...) It is important that there is continuity and that people can trust that I will be there completely. (...) I always try to fulfil my promises." (man, 66)*

Another respondent expressed the core value of wanting to contribute something, when he indicated why he took part in the interview:

> *"if I can contribute to increasing knowledge, and developing insight..., I am a big supporter of that." (man, 50)*

Someone else addressed core values such as respect and taking care of people while discussing his job as a security guard in a hotel and his relationships with his mother, his friends and his mentally deficient aunt:

"If a junky tried to come into the hotel, I thought he was human, just like me and I treated him as a human being. And they appreciated that. They listened to me and they respected me. (...) Of course, own safety first, but I always had a clean lobby, because I treated those people as human beings. (...) I think, if a family member gets ill, and you don't take care of them, you just don't have a soul. (...) I am always prepared to help people, I just do." (man, 49)

Relationships

Relationships are clearly important in the lives of people with stroke. When asked what makes life worthwhile participants often answered in terms of relationships with significant others. Meaningful relationships and the experience of being connected are life goals. One respondent described himself as a loner, a bon vivant, but when the interviewer asked him what was truly meaningful in his life, what made him really happy, his answer was:

"When I see my foster son, that is when I am really happy." (man, 67)

Other respondents gave comparable answers, when asked what they lived for:

"I want to be there for my son, my grandson and my family. Mostly for my grandson and my son." (woman, 57)

"Interviewer: what gives meaning to your life now?
Respondent: my wife and children..., (emotionally) yes." (man, 67)

Worldview

Based on the narratives of the respondents and literature on global meaning,[15] worldview can be defined as fundamental beliefs about life, death and suffering. When respondents looked for explanations for the events that happened in life, their worldview would give structure to their ideas on how these were related. This helped them to find meaning. Their worldview provided an answer to the question why things happen. Worldview became pre-eminently clear when people expressed their view on suffering and their reaction to stressful life events. For one respondent life was an assignment. He saw his suffering as something he deserved. This guided his reaction to what happened and helped him to find the motivation to go on. Because he thought he 'had it coming' he also felt he had to move on and still make the best of it, however difficult this might be:

"Life is an assignment. An order to make the best of it. (...) And suffering, I am afraid that I had it coming. The way I was living ..., that I deserved this." (man, 50)

The answers to the question why things happened, differed. However, if they satisfied the person involved, they were worldviews that gave structure and therefore meaning. This 77-year old woman, for example, said she looked at the world in a contemporary way, which worked well for her:

"Well, I sometimes think that we are driven by a big computer or something, you know. That I think of something and it happens, and I think: 'wow, that is remarkable, well, I guess it ended up in the computer.' (...) I mean, some people call it God, but well, I think in more contemporary metaphors." (woman, 77)

Identity

After stroke respondents often showed differences in behavior and capabilities, which raised questions regarding their identity. Identity refers to fundamental beliefs about one's deepest self. In the narratives of the respondents, identity comprised two aspects that supplemented each other. On the one hand respondents distinguished themselves from others. Expressing their identity was a way of underlining their uniqueness, an expression of self-worth, which gave meaning to their lives. On the other hand, participants described their identity in stressing their being part of specific groups. This provided a sense of belonging, which also gave meaning. Both aspects of identity are shown in the following quote, in which the respondent pointed out characteristics that were unique for her, distinguishing her from other people, but also partly connecting her to others with the same background:

"I was always very active. (...) I travelled a lot, I was a belly-dancer for my hobby. (...) being a dancer, that was my identity, that and being a physician. (...) I am an independent woman, from a socialist, big-city environment, who is relatively well educated. I am a Chinese-Indonesian, and very Dutch, which I noticed during my travels." (woman, 44)

The importance of belonging to a group as part of a person's identity is illustrated in the following quote. This respondent grew up in a working-class family. He never felt completely that he belonged there because he felt he had greater intellectual skills and ambition than was to be expected in his social class. He went to university to study psychology but he never really felt he belonged there either:

"I am an optimistic person, there is enormous strength in me. (...) I am a fighter; I want to go on. (...) I am glad that my intellectual possibilities have not changed. (...) I come from a working-class family. In my time at university, I was often argumentative. I always felt: I don't belong to this group, but neither to the other." (man, 66)

Another respondent described himself as direct and helpful. The fact that his friends appreciated him for that, gave his life meaning:

"I'm just someone that is direct, either you like me or you don't. And... I don't care if you like me or not. I am willing to help people, and I do if I can. I hear from my friends and acquaintances that, whenever I am there, that they feel happy, because I am quick at making contact and jokes and stuff." (man, 49)

Inner posture

When confronted with painful events in their lives respondents tended to encourage themselves or to calm themselves with prayer or meditation or they reminded themselves of what they had learned earlier in life. This helped them to bear what could not be changed. But also when confronted with good things in life they showed a tendency to react in a characteristic way. Inner posture includes an element of acknowledgement and an element of choice and action. It involves acknowledging facts of life and choosing how to relate to them. Respondents did so in different ways. One respondent for example

showed an inner posture of looking at the positive side of things by reminding himself of the good things that were left and comparing himself to others who were worse off:

"I look at others and think that I must not whine, it could have been worse. (...) I miss doing things I used to do, but then I think 'count your blessings'." (man, 65)

Another respondent showed an inner posture of taking things lightly and enjoying the small things in life. This could be seen during the entire interview; it was shown in the tone of his voice as well as in his choice of words. His stroke affected his sight and he was temporarily living in a nursing home while his wife was still living in the house they used to share:

"I can easily adjust to the circumstances. That is something I always was able to. (...) Of course I sometimes think: 'gosh, I haven't improved, have I,' but most of the time that blows over. I enjoy the small things, trying to read a book, trying to look at the television, messing around the house a little. (...) Or when my wife comes and says: 'let's take a stroll.' Then I am really contented, I must say." (man, 68)

Continuity and change in global meaning

Respondents reported both continuity and change in global meaning. This respondent's core value of contributing to society did not change:

"I think it is very important that one... despite my handicap that I contribute something to society. I still feel that way and I made a deal with the school where I had a volunteer job: as soon as I can, I'll be back." (woman, 46)

This also holds for this respondent's relationships and identity:

"(own name) is still (own name). He can't do as much as he used to. But I do my best. (...) I still help my mother, and my aunt, who is mentally deficient. I always looked after people. Still do." (man, 49)

The same applies to this respondent's worldview:

"My faith hasn't changed since my stroke. I still like to pray. (...) We have always been religious people, so I just don't ask why." (woman, 57)

Or this respondent's inner posture:

"I live by what comes my way. Essentially I live my life like I did before. I don't live more profoundly nor more superficially." (man, 68)

Continuity in global meaning was reported by all respondents, however, respondents also reported change with regard to worldview (two respondents), inner posture (one respondent) and identity (seven respondents).

This is shown in the following quote of a respondent regarding her worldview. Before and shortly after her stroke she thought illness was a punishment of God. After realizing that the consequences of her stroke would not go away and that she needed to find a way to live with them, she was not that sure anymore:

"At first I thought 'I am being punished.' I am a roman catholic, so I thought, 'God is punishing me.' ... But now I don't know. Maybe it is fate. ... Things just happen, illness just happens. And this doesn't go away." (woman, 46)

At the same time this woman showed an inner posture that had not changed:

"Don't resign yourself to fate. Just don't give up. Believe in yourself. That is what I always tell my children. Believe in yourself. You may believe in God, we do believe in God, but first you have to believe in yourself." (woman, 46)

In seven respondents changed behavior or diminished skills raised questions regarding their identity. One respondent questioned if she was still the same person now that she was not able to help other people anymore, since this used to be an important part of her identity:

"Yes, I think I have changed, I don't know. (...) I was always the one to help other people, always being there for others. But now I can't do it myself. (...) I don't know... who am I? I am also more emotional than I used to be." (woman, 57)

Discussion and Conclusion

Global meaning in people with stroke

The first purpose of this study was to explore global meaning in people with stroke. We identified five aspects of global meaning in people with stroke: core values, relationships, worldview, identity and inner posture. These are the same aspects we found in our study on global meaning in people with spinal cord injury.[18] The operationalizations of the aspects developed and slightly changed, as compared to the previous study, which is exactly what grounded theory is supposed to be: an emerging theory, that changes and develops during the research process.[25] The main change was, that core values appeared to be not only fundamental beliefs, but also life goals, worthy to be pursued. Besides, we changed the description of worldview from 'Worldview is a more or less coherent set of global beliefs...' into 'Worldview refers to fundamental beliefs...'. Describing inner posture, instead of merely referring to 'the facts' we expanded that to 'the facts of life'. Finally, we refined the descriptions of all five aspects in changing global beliefs and global goals into fundamental beliefs and life goals. (Table 2)

Table 2: *Aspects of global meaning*

Core values	*Relationships*	*Worldview*	*Identity*	*Inner posture*
Core values are fundamental beliefs about what is right and life goals worthy to be pursued. They give direction to thoughts and behaviour.	Relationships refer to a connection between a person and others. Meaningful relationships and the experience of being connected are life goals.	Worldview refers to fundamental beliefs about life, death, and suffering, that structure people's ideas on how life events are related.	Identity refers to fundamental beliefs about one's deepest self. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth.	Inner posture helps people to bear what cannot be changed. It includes an element of acknowledgement and an element of choice and action. It involves acknowledging the facts of life and choosing how to relate to them.

Two of these aspects, namely core values and worldview, have been described in the broad area of stressful life events, but not specifically stroke.[7,13,15-17,26]

In psychological literature on living with stroke *relationships* and *identity* have been found to be of central importance.[1,4,5,21,27-29] Studies on relationships focus on the role relationships play in adaptation to stroke. These studies focus on meaning making processes, rather than global meaning. Our focus was not on the psychological processes of meaning making, but on the more fundamental level of global meaning. Global meaning is hypothesized to play a role in meaning making processes.[7,12] Therefore, our finding that relationships are an aspect of global meaning, corresponds with the abovementioned studies. If global meaning guides meaning making, it is to be expected that relationships as an aspect of global meaning play a role in processes of adaptation to stroke. Studies on identity focus mainly on change in identity after stroke, which we will address later. Most researchers distinguish at least self-identity and social identity, which is in line with our findings that respondents describe themselves as unique and as part of larger groups at the same time.

The term *inner posture* has not been found in previous research.[18] However, using a different terminology, the *concept* of inner posture is found in the fields of philosophy and psychotherapy: the stoics refer to inner posture as 'attitude',[30] while Frankl describes the attitude a person can choose in the face of unavoidable suffering.[14] Inner posture can be seen as related to coping. However, coping strategies are applied in a specific situation,[31] while inner posture refers to the way people deal with life events in general. Inner posture, being part of global meaning, may drive coping processes, which are part of situational meaning.

Both Park and Frankl are important sources for research on meaning. However, Park does not refer to Frankl in her meaning making model, which has been critiqued by Marks.[32] More research on global meaning, specifically attitude and inner posture, and their relationship to meaning making processes is recommended.

Continuity and change in global meaning in people with stroke

A second purpose of our study was to explore whether global meaning changes after stroke. In this study both continuity and change in global meaning were found. All respondents reported continuity in global meaning. Some of them, however, also reported change. Several respondents reported changes in their relationships. The life goal of maintaining meaningful relationships however, did not change. Only the content and the character of relationships changed. So in these instances global meaning did not change.

Continuity and change were found not to be mutually exclusive, but appeared to co-exist. In one interview for example, the respondent's wife reported continuity as well as change with regard to her husband's identity. She distinguished between her husband's changed behavior and her husband 'himself', the latter referring to his character, his self-identity. This seems to indicate a *need for* continuity, which is also mentioned in research

on identity and brain injury.[33] In comparison, the above mentioned quote of the 57-year old woman, who was not able to help other people anymore, seems to indicate that she experienced her identity as changed, because of her changed capabilities. In psychological research on identity in relation to stroke identity change is an important issue.[1,27,28] In different studies different aspects of identity are found to change or stay the same, depending on the definition of identity and the research methods or the questionnaires used.[21,34] Ownsworth states that change can occur as a result of a neurological disorder, a (stressful) life event or more gradually as a result of psychotherapy or self-relevant situational feedback. She states that a person can experience change and continuity at the same time, which is in line with what our respondents reported.[21]

The change in global meaning found in people with stroke contrasts with the results of our study on global meaning in people with spinal cord injury, in which no prominent changes were found.[18] This may be a result of the fact that after stroke it takes a longer time to reach an end-state, compared to spinal cord injury. Or it may be related to the fact that the consequences of spinal cord injury are mostly physical, whereas stroke has mental and behavioral consequences as well. This is in line with the results of a study on spiritual issues associated with traumatic-onset disability, in which changes were found in people with brain injury, but not in people with spinal cord injury.[35] According to McColl people with brain injury report significantly more changes in identity and relationships compared to people with spinal cord injury.[35] The change found in people with stroke may be related to cognitive and behavioral changes as a result of stroke.[34,35]

Methodological considerations

In this study the five aspects of global meaning that were found in people with stroke, were the same aspects that were found in people with spinal cord injury. This may have been a result of the questions that were asked by the interviewer, because the topic list was initially developed in interviews with people with spinal cord injury. However, both researchers who analyzed the interviews were cautious to keep an open mind to other possible aspects of global meaning. Nevertheless, they both independently found the same five aspects.

The time span of 4-26 months after admission to the rehabilitation center is a rather long one. Therefore, it is to be expected that respondents were in different phases of adaptation to living with a stroke. Nevertheless, all respondents were in outpatient rehabilitation and in a process of adapting to a new situation: living with the consequences of a stroke. We did not study in exactly what phase of adaptation respondents were; however, they did report about all five aspects of global meaning. Hence, it is not likely that the phase of adaptation was of influence on the content of global meaning. However, some respondents reported change in, for example, their identity or worldview. So, in their experience, the expression of different aspects did change. Since we did not study the different phases of adaptation, it is possible that the reported changes are connected to the phase of adaptation. Therefore, more research is recommended to study the relation between phase of adaptation and perceived change in global meaning.

Besides, the interviews were all conducted in the first period after a first stroke, which may account for the fact that many questions were still open, and continuity and change were found to be co-existing. After stroke, it takes a long time to reach a stable final situation. Longitudinal studies are recommended to explore if global meaning changes after a longer period of living with stroke.

Since the interviews took place after stroke, they reflect the view of the respondents in retrospect. As a result, we cannot be sure if the reported change or continuity was, at least partly, a result of retrospective bias or was affected by memory problems or lack of insight relating to stroke. This problem could be addressed by interviewing relatives of the respondents, which may be an interesting field of future research. However, our results show how respondents reflected on their current and former global meaning. Since global meaning is hypothesized to guide meaning making processes, it may not be very relevant whether global meaning *actually* changes. If in the experience of the person with stroke it does, this needs to be addressed. Perceived changes in global meaning tend to create distress, which initiates meaning making processes.[7,11,12]

In the interviews with respondents with whom the first author had a close counselling relationship, she was extra careful in following the topic list during the interview. She was aware of the fact that the interviews needed to be understandable for other researchers as well and she checked regularly with the person who transcribed the interviews whether she thought the researcher was taking things for granted. The fact that a relationship already existed may have resulted in faster arriving on the level of global meaning. However, this does not mean that in the other interviews the level of global meaning was not reached, since the interviewer is an experienced spiritual counsellor, who is used to establishing a relationship and helping people to reach deep levels of introspection, whether they already know her or not.

In some interviews a spouse or another family member was present. This can be seen as both a limitation and a strength. On the one hand, the respondent may not have told everything, because they wanted to protect their family from certain ideas. On the other hand, the spouse or family member sometimes stimulated the respondent, by reminding them of earlier actions or statements they themselves did not think of telling or by complementing the story of the respondent with their own view on the situation.

Conclusion

In this study, five aspects of global meaning in people with stroke were found: core values, relationships, worldview, identity and inner posture. These are the same aspects found in research on global meaning in people with spinal cord injury.[18] More research is needed to explore global meaning in different groups of people or in the general population, to explore if these aspects are specific for people with, for example, neurological disorders, or whether they are related to stressful life events in general, or if they are universal.

People with stroke reported continuity as well as change in their global meaning. Continuity and change were found to co-exist rather than being mutually exclusive. Sometimes continuity and change were found in different aspects of global meaning, one aspect changing and the other not. But especially in identity, continuity and change appeared to be present at the same time. Future research is recommended to explore continuity and change in global meaning over a longer period of time.

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Declaration of Interest

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Appendix 1

Topic list *global meaning*

1. Could you tell me what happened to you?
2. What has changed?
3. What has remained the same?
4. Do you think your stroke has a meaning or a purpose?
5. Do you think life in general has a meaning or a purpose?
6. What is really important to you in life?
7. When do you get annoyed?
8. What do you hope others will say or think about you?
9. If I ask you: 'Who are you?' what would be your answer?
   (Please finish the sentence: I am … someone who …)
10. Could you share some of your thoughts about death with me?
11. How do you manage to live with your stroke?
12. Has what we have discussed so far affected your rehabilitation? In what way?
13. Is there anything else you would like to say, in reaction to the interview so far?
14. How did you experience this interview?

Addendum to the data analysis section of chapter 4 (not published)

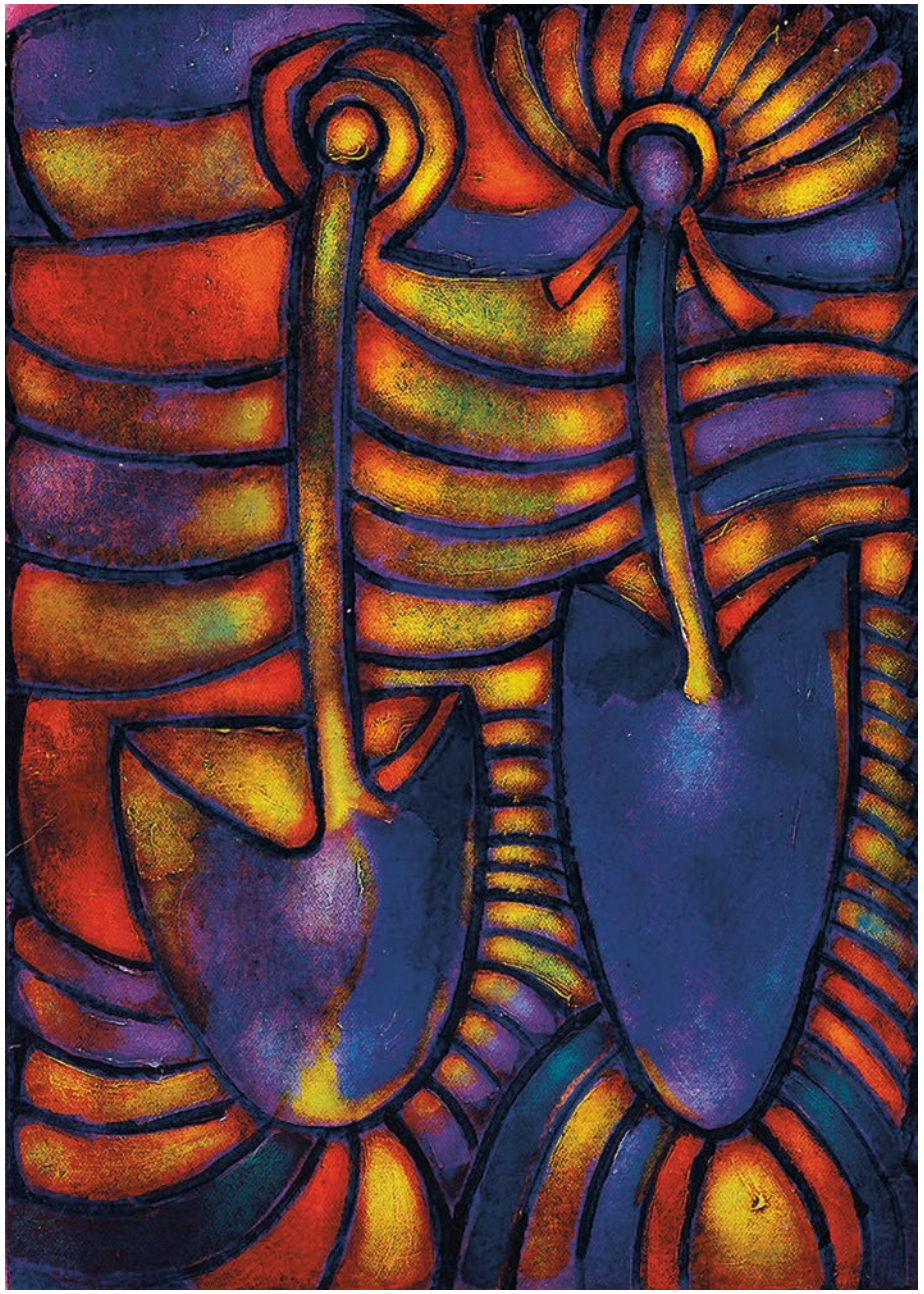
In order to analyze the data verbatim transcripts were made of the recorded interviews, which were then analyzed by two researchers using the method of grounded theory. Data were entered into a software program for qualitative data analysis and research, Atlas.ti (version 7.1.6). The analysis was based on the transcribed interview recordings, using the interviewer's impressions, reported in field notes, as background material. The actual recording was readily available through Atlas.ti, and was used for listening to the tone of statements and remarks. Although previous research on people with spinal cord injury had already shaped ideas about global meaning, the researchers who analyzed the interviews were especially focused on the possibility that the interviews with people with stroke might provide different outcomes. They regularly discussed their findings with the other researchers, in order to stay as open-minded as possible. In grounded theory, a theory is developed during the process of interviewing and analyzing, constantly testing assumptions and gradually adapting ideas. Therefore, in order to be as open as possible, the researchers started the analysis by 'open coding' the transcripts of the interviews, while keeping close to the text, to allow for the possibility that different aspects of global meaning might be found in people with stroke, as compared to people with spinal cord injury. This led to 388 codes.

The codes were grouped into 19 concepts and these concepts were gathered into larger categories, which the researchers assumed to be aspects of global meaning. When eight interviews had been conducted, transcribed and analyzed in this way, an overview was made of the aspects of global meaning found in each interview. On the basis of these overviews and categories the next interviews were analyzed searching for these and different aspects of global meaning, continuity and change. The concepts and the larger categories were discussed in the research group.

When the analysis reached its saturation point at 12 interviews, five aspects of global meaning had been clearly identified from the data. The last 4 interviews brought no new information to light. The relation of the 19 concepts and the larger categories that became the five aspects of global meaning is illustrated in Box 1.

Box 1. *Relation between the five aspects of global meaning and the 19 concepts*

Core values	*Relationships*	*Worldview*	*Identity*	*Inner posture*
Acceptance	Dependence	Cause of stroke	Comparing with others	Acceptance
Putting in perspective	Professionals	Changes	Dependence	Comparing with others
Reflecting	Relationships	Death	Dreaming	Dreaming
Values	Work	Learning	Identity	Hope
Work		Putting in perspective	Learning	Learning
		Suffering	Putting in perspective	Putting in perspective
			Reflecting	Rehabilitation
			Relationships	Suffering
			Work	Understanding



Karmische scheppen *Ten gevolge van mijn beroerte had ik last van een sleepvoet wanneer ik lange strandwandelingen maakte met mijn vrouw Marjan. Door appeltaart met slagroom in het vooruitzicht te stellen hield ik het vol. Mijn sleepvoet geneest door deze wandelingen of deftig gezegd: door het zelfscheppend herstelvermogen. Ik heb geen klapvoet die mij rolstoelafhankelijk zou maken. Marjan zou de rolstoel door het mulle zand moeten slepen met mijn lijf daarin. Als ik een klapvoet had zou onze strandwandeling onmogelijk zijn.*

Chapter 5

Global meaning and rehabilitation in people with stroke

Elsbeth Littooij

Joost Dekker

Judith Vloothuis

Guy AM Widdershoven

Carlo JW Leget

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Abstract

A stroke can have implications for all areas of a person's life. In research on adaptation to stroke, finding meaning is associated with better adaptation. This study focuses on one of the driving principles behind meaning making processes: global meaning. The aim of this study was to explore whether global meaning (that is, fundamental beliefs and life goals concerning core values, relationships, worldview, identity and inner posture) is associated with processes and outcomes of rehabilitation, as experienced by people with stroke. In-depth, semi-structured interviews were conducted with 16 people who sustained a stroke for the first time, and analyzed using qualitative research methods. Aspects of global meaning were associated with the following elements of process and outcome of rehabilitation: motivation, handling stress and emotions, interaction with rehabilitation professionals, physical functioning and acceptance. The influence was mostly positive. If rehabilitation professionals took global meaning into account, respondents tended to associate this with quicker or better recovery. This suggests that it is important for rehabilitation professionals to address their patients' global meaning. Addressing global meaning may lead to greater patient satisfaction and better rehabilitation care.

Introduction

A stroke can have implications for all areas of a person's life. Among the reported consequences of stroke are physical and cognitive problems, depression, anxiety and social isolation.[1-5] Most people who sustain a stroke need rehabilitation, in order to adapt to the physical and psychological consequences. Research on adaptation to stroke has shown that finding meaning is associated with better adaptation:[3] use of the coping strategy 'finding meaning' was a significant predictor for less depression and better adaptation. The same applies to engaging in meaningful activities:[1] people who were able to maintain participating in activities that were meaningful to them, showed better adaptation post stroke.

In a review of the meaning literature, Park developed a meaning making model, in which she differentiated between global meaning and situational meaning.[6] The term 'global meaning' refers to fundamental beliefs (regarding justice, control, coherence, et cetera) and life goals (such as relationships, work, religion, or knowledge). Global meaning provides individuals with cognitive frameworks to interpret their experiences and to motivate them in their actions. Global meaning influences the meaning making processes that are part of situational meaning. Situational meaning refers to meaning making processes in specific situations.

Park hypothesizes that global meaning plays an essential role in adjustment to serious illness.[6,7] In a previous qualitative research project, we interviewed people with stroke and used a grounded theory approach to analyze their ideas about and experiences with global meaning. We found that global meaning in people with stroke comprises five interlinked, yet distinguishable aspects, namely core values, relationships, worldview, identity and inner posture.[8] Based on the narratives of the respondents and literature on the subject, we defined *core values* as fundamental beliefs about what is right and life goals worthy to be pursued. They give direction to thoughts and behavior.[9] *Relationships* refers to a connection between a person and others, for example, children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are life goals. Based on the interviews and on literature, we found that *worldview* can be seen as a set of fundamental beliefs about life, death, and suffering, that structure people's ideas on how life events are related.[10] *Identity* refers to fundamental beliefs about one's deepest self. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth.[11,12] Besides these aspects of global meaning, we identified a fifth aspect, which we named 'inner posture'. When confronted with challenging consequences of their stroke, respondents tended to encourage or calm themselves with prayer or meditation, or they reminded themselves of what they had learned earlier in life. This seemed to help them bear these consequences. *Inner posture* refers to the way in which people bear what cannot be changed, which is an important goal in life. Inner posture includes an element of acknowledgement and an element of

choice and action. It involves acknowledging the facts of life and choosing how to relate to them.[8]

Given the fact that finding meaning is associated with better adaptation,[3,13] and Park's hypothesis that global meaning plays a role in adjustment to serious illness,[6,7] it can be hypothesized that global meaning may influence rehabilitation in people with stroke. Although little is known about the relation between global meaning and rehabilitation in people with stroke, aspects of global meaning have been described in research literature: worldview and core values have been described in the broad area of stressful life events, but not specifically stroke.[6,9,10,14-16] In psychological literature on living with stroke, relationships and identity have been found to be of central importance.[12,17-22] However, these studies focus on the role relationships play in adaptation to stroke and on identity change after stroke. Hence, they focus on meaning making processes and not on the more fundamental level of global meaning. Therefore, the aim of this study was to explore the association of global meaning with processes and outcomes of rehabilitation as experienced by people with stroke.

Methods

Design

This qualitative study is part of a larger study on global meaning in people with spinal cord injury or stroke. In a previous phase of the study, we identified the *content* of global meaning in people with stroke.[23] In the present study, we explored the way in which people who experienced a stroke associated their global meaning with their rehabilitation. We interviewed people with a stroke and analyzed the interviews using a grounded theory approach. Central in this approach are the experiences of the respondents and the meaning they give to their experiences. In grounded theory, data collection and analysis becomes more focused as the study and theory evolves.

Ethics approval

The study was approved by the accredited Medical Research Ethics Committee Slotervaart Hospital and Reade (METC-study number P1153).

Participants

Participants were people who had sustained a stroke for the first time, and were receiving outpatient treatment at a Dutch rehabilitation center. Participants were purposefully selected to include both men and women and people with a more optimistic and a more pessimistic attitude, according to the physician assistant in attendance. Inclusion criteria were: adults, over 18 years of age, attending outpatient rehabilitation, living in the community with a stroke, and being able to engage in a conversation. Clients with severe communication problems were excluded. Approximately half of the respondents were familiar with the two spiritual counselors in the rehabilitation center, of which the first author is one. The relationships between researcher and participants ranged from an intensive counselling relationship to being unacquainted.

Procedure

Semi-structured interviews were conducted by the first author, who is an experienced spiritual counselor. A spiritual counselor, sometimes referred to as healthcare chaplain, or existential counselor, supports people when the self-evident order of everyday life is broken; in situations of life and death, in the event of farewell and loss, in the case of experiences of great connection or of abandonment, and in ethical questions. They are proficient in dealing with life questions, meaning, spirituality and ethical considerations.[24]

Interviews were held between 4-26 months after admission to the rehabilitation center. Potential participants were selected using a mix of purposive sampling and snowball sampling. A letter was sent to potential participants to which they could respond by returning a consent form (purposive). Furthermore, people who spontaneously applied for participation in the study, because they heard about it from other participants, were also included if they met the inclusion criteria (snowball). In these cases, the invitation letter was sent to them as well, and they were admitted after signing the consent form. In the invitation letter supplementary counseling was offered, if participants wanted to further reflect on the subjects raised in the interview. One participant made use of this option and received supplementary counseling provided by the first author.

Data collection

The main method of data collection consisted of semi-structured interviews with 16 participants which, with permission of the participants, resulted in 16 audio-recordings. The majority of the interviews took place at the participants' homes. On average interviews ran for approximately one hour, the shortest being 47 minutes, the longest 1 hour and 38 minutes. They were conducted between October 2013 and July 2014. The interviewer registered in field notes the observations she made before, during and after the interview, giving details that could not always be heard on tape, such as the occasional presence of a partner or an adult child, and nonverbal aspects of the communication.

Interviews were loosely structured using a topic list based on literature concerning global meaning[6,9,10,14,25,26] and on previous research on global meaning in people with spinal cord injury.[27] (see Appendix 1) The last part of the interview focused on rehabilitation. One of the questions was 'Has what we have discussed so far affected your rehabilitation? In what way?'. The interviewer did not use these exact words, but she would summarize the conversation so far and then elaborate on the perceived influence on processes and outcomes of rehabilitation.

Data analysis

Verbatim transcriptions were made of the recorded interviews, which were then analyzed by the first author, using structural, provisional and elaborative coding.[28] In the structural

Table 1: *Respondent characteristics*

Characteristics	Mean (range)
Age (years)	59.25 (42-77)
Time post-injury (months)	13.31 (4-26)
	No.
Sex	
Male	11
Female	5
Country of birth	
Netherlands	13
Suriname	2
Curacao	1
Social status	
Single	6
Single with children	1
Married/living together with children	1
Married/living together without children	7
Living apart together	1
Education	
Vocational training	4
High school	3
Community college	2
Undergraduate school	2
Graduate school	5
Religious background	
Christian	4
Atheist	2
Humanist	1
None	9

coding phase, the researcher structured the interviews in line with the research question about the relationship between global meaning and rehabilitation, and identified quotes about processes and outcomes of rehabilitation, using the codes 'rehabilitation', 'process' and 'outcome'. Processes and outcomes were differentiated, following Donabedian's quality of care framework.[29] He describes processes as patient's and practitioner's activities in receiving and giving care, including technical and interpersonal processes. Outcomes he describes as the effects of care on the health status of patients.

In the second phase of the analysis, the quotes were analyzed provisionally. Regarding global meaning, we used aspects of global meaning as codes (core values, relationships, worldview, identity, inner posture). Regarding processes and outcomes of rehabilitation, we used the International Classification of Functioning, Disability and Health to create codes (e.g. motivation, handling stress and emotions, making decisions, physical functioning, emotional functioning, social functioning, quality of life).[30] We searched for overlaps and relations between the coded quotes, to identify which processes and outcomes respondents associated with their global meaning, and to find relationships between global meaning and the various processes and outcomes of rehabilitation. The quotes coded with the same codes were compared and when appropriate, similar codes were grouped together under one theme, again using the ICF. The preliminary outcomes were regularly discussed with the other researchers, in order to deepen and intensify the analysis.

In the final phase of the analysis elaborative coding was used to determine in what way global meaning affected processes and outcomes of rehabilitation as experienced by the respondents. Data were entered into a software program for qualitative data analysis and research, Atlas.ti (version 7.5.6). The analysis was based on the transcribed interview recordings, using interviewer's impressions, reported in field notes, as background material. The actual recording was readily available through Atlas.ti, and was used to listen to the tone of statements and remarks.

Results

Out of 27 invitation letters and 4 spontaneous applications, 16 people reacted positively by sending back the consent form. Eleven of them were male, five were female. Their age ranged from 42 to 77. (see Table 1) One respondent was living in a nursing home, the other 15 in the community.

The analysis reached a saturation point at 12 interviews, after which 4 more interviews were conducted, that added no new information.

Three themes were identified which pertained to how global meaning influenced rehabilitation processes: (i) fostering motivation, (ii) handling stress and emotions, and (iii) interaction with rehabilitation professionals. The first two themes were derived from the ICF, the last was created based on the narratives of the respondents.

Regarding the outcome of rehabilitation, two themes were identified: (i) physical functioning, and (ii) acceptance.

All respondents alike mentioned these elements: men as well as women, younger and older respondents, respondents with right- and left hemispheric injury and respondents from different cultural backgrounds.

Three aspects of global meaning, namely relationships, identity and inner posture, were mentioned regularly relating to processes and outcomes of rehabilitation. Core values and worldview were only mentioned by a few respondents.

Overall, the influence of global meaning on processes and outcomes of rehabilitation was described as positive: respondents felt that their motivation, their ability to handle stress, their physical functioning and their ability to accept their life after stroke improved because of their global meaning. In several cases this influence was dependent on the way in which rehabilitation professionals addressed the global meaning of their clients.

Influence of global meaning on processes of rehabilitation

Motivation

Respondents described relationships, worldview, identity and inner posture as sources of motivation, and used them more or less consciously. In the interviews, respondents reflected on relationships as life goals that motivated them to do their exercises and carry on with their rehabilitation and with life. Worldview and identity were mentioned as resources that provided motivation to rehabilitate, while an active and positive inner posture in itself was providing motivation to carry on doing their exercises and not give up on rehabilitation.

One respondent for example wanted to maintain a meaningful relationship with his son. This had always been a life goal for him. He had built up a business, which his son had taken over. Until his stroke, he had regularly come by to help out.

"Regarding my rehabilitation..., the relationship with my son, well, it stimulates me. (...) When he calls me, and asks: 'will you come over to the company today?' Well, that encourages me, I think that is great, for him to think about his father like that, you know, to say 'I want to see you'. Then, however tired I am, I get up and go."

This respondent connected the relationship with his son directly with his rehabilitation. He was motivated to exercise and work on his physical condition, because he wanted to be able to come over, whenever his son needed him.

Another respondent's worldview was that life is an assignment: you need to make the best of your life and of yourself. Corresponding with this worldview, his inner posture was to always do your best. He had acted accordingly since the age of 16 and had become good at his job and the center of many parties and groups of friends. Before his stroke he was already trying to change his lifestyle, because he wasn't sure anymore that success was the goal, but still he was trying to make the best of his life and of himself.

"To do the best you can, for me, is now: searching for a good posture on the couch, taking a book that is as interesting as possible, listen to music and trying to get through the day. So that is what I do. And keeping my appointments. When I have an appointment with the doctor, I go to the doctor, when I have to take my pills, I take my pills."

This quote shows how this person's worldview and inner posture affected his motivation to rehabilitate. Although the goal of his life was already changing before his stroke, he still wanted to make the most of it, given the circumstances. Success was no longer the goal of his efforts, but being the best possible version of himself was.

Handling stress and emotions

Respondents regularly mentioned relationships, worldview, identity and inner posture as helpful in handling the stress and emotions raised by the consequences of their stroke. Relationships and worldview were used to seek comfort and distraction, in order to deal with stress and emotions. Identity and inner posture determined the way in which respondents tried to bear or overcome stress and emotions.

For one woman being connected with her family had always been a life goal. Besides that, her religious worldview was important to her, especially in handling stress and emotions.

"Whenever I am afraid or sad I talk to my mother in heaven. She always was a religious woman and she used to comfort us. Or I listen to religious songs. Or I pick up the phone and call my sister. And one of my uncles, he came regularly to pray with me. That gives peace."

This respondent's religious worldview and her relationship with her family were closely connected, almost intertwined. She identified them as her most important sources in handling stress and emotions, also during her rehabilitation.

Another respondent's identity was defined by his being a sportsman. He described himself as a stubborn, strong, independent person. He was never afraid to show emotions, but up until his stroke, the emotions he experienced were mostly frustration or anger, related to his sports.

"Whenever I had a hard time in rehabilitation I used to cry. I don't go looking for help, or something. I think I have to overcome it by myself. I never went to support groups or something, that's just not me."

This quote shows how this respondent's identity affected his way of handling stress and emotions. He was not afraid to show his grief, but being an independent person, he dealt with it by himself, not wanting to bother other persons, nor needing them.

Interaction with rehabilitation professionals

The experience of rehabilitation was influenced by the way in which rehabilitation professionals addressed the global meaning of their clients. Not connecting to their clients' global meaning lead to conflict in several cases. For example, one respondent's core values of being useful, and of respect, responsibility and independence influenced

how he treated others and how he liked to be treated himself. This also played a role during his rehabilitation.

"When I saw my schedule in the rehabilitation center I thought I might as well be at home. They gave me so little to do. So the physical therapist said that it was okay if I came and trained by myself. So that was good. And then I got into a dispute with the doctor. For I was having a beer with a fellow patient and the doctor said that I couldn't. I could understand that if I got drunk every day, but one beer! And then the doctor said that it was not healthy for my companion. What am I, his guardian? He is a grown man, I couldn't tell him what to do and what not to do, could I? I wouldn't want to."

This respondent's core values were met by his physical therapist, which he appreciated. But they brought him in conflict with the physician, who, in his experience, wanted him to act against his core values of respect, responsibility and independence.

If rehabilitation professionals took global meaning into account, respondents tended to associate this with quicker or better recovery. For example, one respondent showed an inner posture of searching for information, looking for confirmation, and then going his own way again. He had done so all of his life and that hadn't changed after his stroke.

"I really appreciated the nurses and the physical therapists. Whenever I wanted something, they would listen and tell me what I needed to know. (...) They could see the progress every day and I was home within three months."

The confirmation and information the rehabilitation staff provided when needed, corresponded well with this respondent's inner posture. He connected this with his quick recovery. As a result of this he experienced his time in the rehabilitation center as very positive.

Influence of global meaning on outcomes of rehabilitation

Physical functioning

Respondents identified relationships, identity and inner posture as important elements in the improvement of their physical functioning. The life goal of the relationship with one's children, or the identity of a winner, or an inner posture of setting goals and trying, even when you are afraid, in respondents' experience, were directly related to improvement of strength or function.

For one respondent, her children were the most important thing to give meaning to her life. After her stroke she feared not being able to take care of her children the way she used to. She was right-handed and after her stroke she suffered a decrease of strength in her right side.

"I used to make breakfast and lunch for my daughters, that was my passion, being their mother. That is what I wanted to be able to do again. And that is what I achieved. I wanted to make that sandwich, for them to take and eat and think 'my handicapped mother made that for me'."

This mother connected her being able to make lunch and breakfast again with the importance of the relationships with her daughters. She felt that the importance of fulfilling her duties as a mother helped her to overcome the physical difficulties and to regain enough strength in her right arm.

Acceptance

Respondents experienced an influence of core values, relationships, identity and inner posture on the acceptance of their stroke. They felt that their global meaning helped them to live with their stroke and to accept it. Some of them were still in the process of accepting, others had accepted without a struggle. Core values and relationships were catalysts to acceptance. They helped people in accepting the consequences of their stroke. In some respondents, acceptance seemed to be part of their identity or inner posture, whereas in others, it was not.

In one respondent for example, his inner posture of not giving up strengthened his motivation to rehabilitate, however, it interfered with accepting his changed possibilities. For another respondent, relationships had always been a life goal. This was closely connected to his core value of responsibility for each other when living in a community and to his inner posture of living with whatever life offers you. This did not change after his stroke. Before his stroke he already took care of his mother, who suffered from dementia, and of his daughter, and he looked after his aunt, who was mentally challenged from childhood on.

"Taking care of my family, that is still important, even though I have had a stroke. (...) I think it is important to live in a community and to make life happier for other people. For instance, in the rehabilitation center, I tried to make a good atmosphere. We ordered pizza's or drank a beer, watched a movie, and then to bed. I always say: learn to live with it. And I do."

After his stroke, this person tried to maintain taking care of other people. He also tried to do so in the rehabilitation center, when he was in inpatient rehabilitation. Finding new ways of taking care of other people, even in the rehabilitation center, helped him to live with his stroke and accept his changed life. In this process, his inner posture was a direct source of acceptance, for 'accepting whatever life brings' was a part of his inner posture.

Discussion

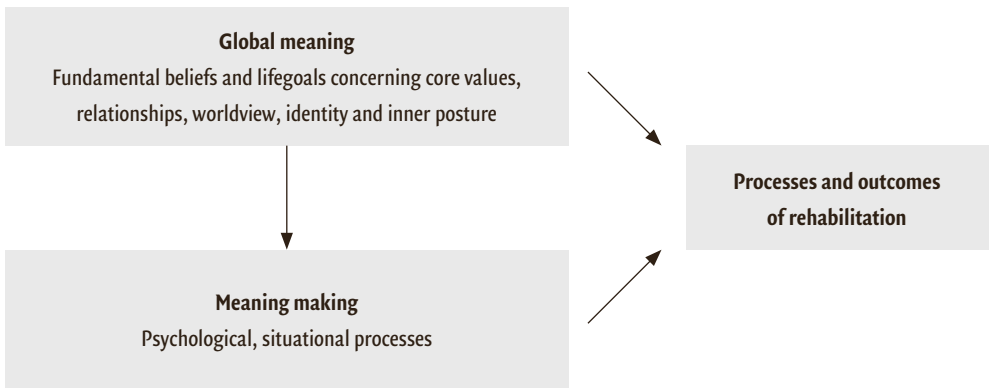
In this study we explored how people with stroke experienced the relationship between global meaning and processes and outcomes of rehabilitation. We found that three of the five aspects of global meaning, namely relationships, identity and inner posture, were often mentioned as factors contributing to processes and outcomes of rehabilitation. Core values and worldview were mentioned less. Respondents reported a perceived influence on motivation, handling stress and emotions, interaction with professionals, acceptance and physical functioning. We found these elements in men and women, younger or older respondents, respondents with right- or left-hemispheric injury and in respondents

with different cultural backgrounds. The content of the core values, relationships, worldviews, identities and inner postures differed, but all respondents reported the experience of aspects of global meaning affecting rehabilitation. Overall this influence was experienced as positive: respondents reported that their motivation, the ability to handle stress and emotions, their physical functioning and the acceptance of their life after stroke benefited from their global meaning.

In some situations, a direct influence of global meaning on rehabilitation was experienced, whereas in other instances global meaning seemed to be a source or a catalyst for meaning making processes (i.e. situational meaning). These processes in turn may have affected rehabilitation. (see Figure 1) These findings are in line with research considering the influence of meaning making processes on adaptation to a stressful life event such as a stroke.[1,3,5-7,13,31]

In an earlier study on global meaning and rehabilitation in people with spinal cord injury[32] all five aspects of global meaning were found to affect processes and outcomes of rehabilitation. This is in contrast with the current study, in which core values and worldview were mentioned far less. However, it is in line with research on aspects of global meaning regarding people with stroke. In literature on *spirituality* and health in people with stroke,[33] no relation was found between physical outcomes and religion or spirituality. However, in research on first-stroke recovery processes,[34] *family social support* was associated with progressive improvement of functional status. Spirituality can be seen as related to the 'worldview'-aspect of global meaning and family social support is related to 'relationships'. Therefore, our finding that worldview was mentioned less than relationships, appears to correspond with the abovementioned studies. However, since our study is a first exploratory study on global meaning in rehabilitation of people with stroke, more research on all aspects of global meaning and their influence on rehabilitation is recommended.

Figure 1: *Perceived influence of global meaning on rehabilitation*



Respondents expressed more contentment with their rehabilitation, if rehabilitation professionals addressed issues of global meaning. They associated fast or good recovery with the way in which professionals connected to these issues. When professionals did not address global meaning, this was experienced as a source of possible conflict. Based on the quotes in which respondents addressed this issue, we hypothesized that this may have to do with *not* addressing global meaning, or with *differences in* global meaning between the professional and the respondent (for example different worldviews or core values). If the latter is the case, it is recommended that rehabilitation professionals are aware of possible differences in global meaning and that they attune to the global meaning of their patients. Cole states that in rehabilitation the relationship between patient and professional is more equal than in the hospital.[35] This is in line with our finding that respondents appreciated the connection of rehabilitation staff with their identity, core values or inner posture. If, for example, a professional treated a rehabilitant with an identity of an independent, self-supporting person as an equal, that motivated the rehabilitant to give his best in rehabilitation.

Study limitations

In this qualitative study we assessed how respondents experienced the role of global meaning in their rehabilitation. It shows that according to people with stroke global meaning is important in processes and outcomes of rehabilitation. All respondents reported an influence of aspects of global meaning on process and outcome of rehabilitation. However, selection bias cannot be excluded: respondents may have had a prior interest in global meaning. We do not have information from the 15 people who did not sent back the consent form to take part in the study on why they did not react.

The relationships between researcher and participants varied, ranging from an intensive counseling relationship to being unacquainted. The existence or absence of a counseling relationship between respondent and researcher prior to the interview may have influenced the results.

One of the consequences of stroke may be the experience of cognitive problems. We did not explore in which way this interfered with respondents' ability to reflect and give words to their ideas on global meaning and rehabilitation. We did observe that respondents differed in their ability to formulate their life goals and fundamental beliefs. Whether this was a result of their stroke has not been studied.

This is a first, exploratory study on how people with stroke experience the influence of global meaning on rehabilitation. The research group was small, and we did not differentiate between, for example, different sides of injury, sex or age. The only inclusion criteria we used were 'first stroke' and outpatient rehabilitation. Respondents were to be still in an early phase of adaptation, but not in acute rehabilitation anymore. Further research in larger groups of people with stroke is recommended in order to replicate our findings and to explore possible differences related to side of injury, time since injury, cultural background, sex or age.

Conclusion

In this qualitative research project, it was identified that aspects of global meaning, namely relationships, identity, inner posture and, to a lesser extent, core values and worldview influenced rehabilitation. The elements of rehabilitation participants mentioned in relation to their global meaning were motivation, handling stress and emotions, interaction with professionals, physical functioning and acceptance. The influence was mostly positive. If rehabilitation professionals addressed their patient's global meaning, this facilitated rehabilitation. This suggests that it is important for rehabilitation professionals to address their patients' global meaning. Addressing global meaning may lead to greater patient satisfaction and better rehabilitation care.

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Ethical standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

Conflict of interest

Elsbeth Littooij has no conflict of interest to disclose.
Joost Dekker has no conflict of interest to disclose.
Guy Widdershoven has no conflict of interest to disclose.
Judith Vloothuis has no conflict of interest to disclose.
Carlo Leget has no conflict of interest to disclose.

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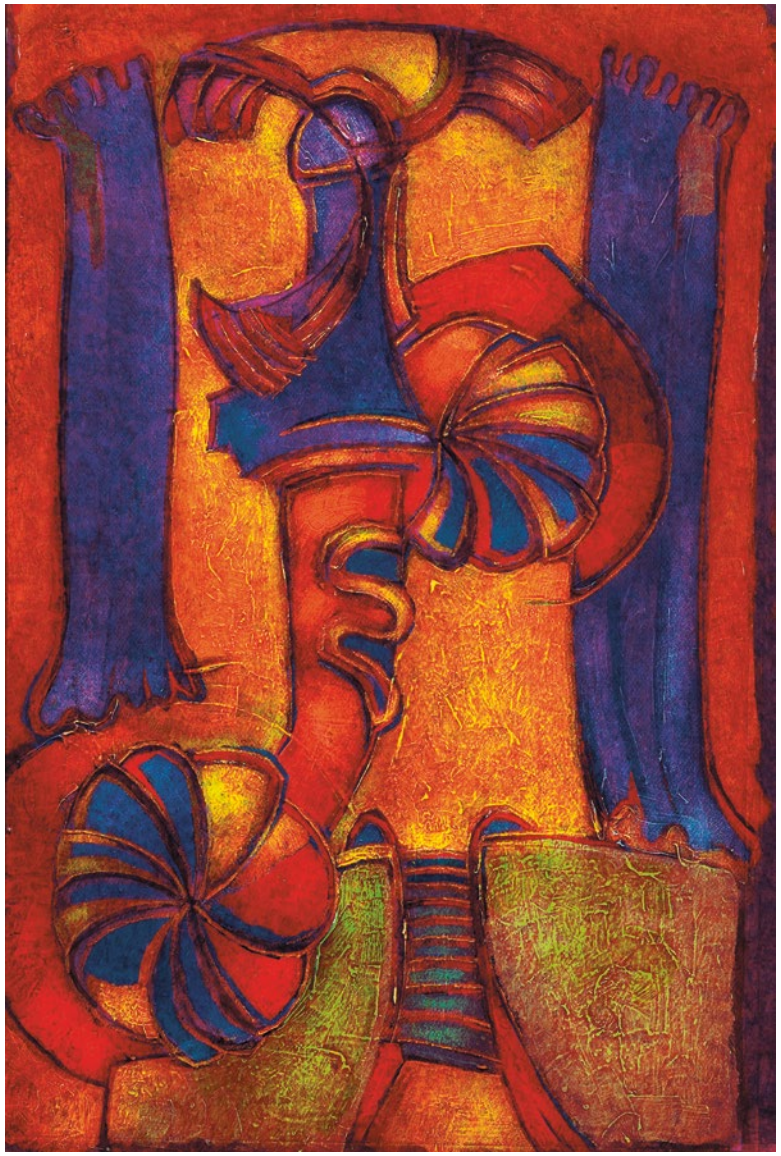
Appendix 1

Topic list *global meaning*

1. Could you tell me what happened to you?
2. What has changed?
3. What has remained the same?
4. Do you think your stroke has a meaning or a purpose?
5. Do you think life in general has a meaning or a purpose?
6. What is really important to you in life?
7. When do you get annoyed?
8. What do you hope others will say or think about you?
9. If I ask you: 'Who are you?' what would be your answer? (Please finish the sentence: I am … someone who …)
10. Could you share some of your thoughts about death with me?
11. How do you manage to live with your stroke?
12. Has what we have discussed so far affected your rehabilitation? In what way?
13. Is there anything else you would like to say, in reaction to the interview so far?
14. How did you experience this interview?



De molen van Piet *Tijdens mijn beroerte schoof de verpleegster in mijn ziekenhuiskamer iedere morgen met een zwaai de gordijnen open en bood mij een schitterend uitzicht op de molen van Piet. Ze begroette mij met een krachtig 'Goedemorgen wil je koffie?' Ik had geluk met die molen. Een beroertepatiënt heeft behoefte aan een mooi uitzicht in plaats van tegen een blinde muur aan te moeten kijken. Want een blinde muur maakt dat je het leven niet meer ziet zitten. En allerlei sombere vragen doet stellen zoals: 'Wat is de zin van mijn beroerte?' Vragen waar niemand antwoord op heeft. 'Wil je koffie?' De koffie was heerlijk in het ziekenhuis, althans in Alkmaar waar ik de beroerte lag uit te liggen. Ik maakte iedere dag een tekeningetje om mijn innerlijke toestand in kaart te brengen. En deze tekeningen hadden deze schilderijen tot gevolg. Ik noem het mijn Beroerteserie. Het is bedoeld om permanent tentoongesteld te worden in een speciale zaal van een vooruit strevende revalidatie kliniek. Als 'Een wonderlijke reis'!*

Chapter 6

Inner posture as aspect of global meaning in healthcare: *a conceptual analysis*

Elsbeth Littooij

Guy AM Widdershoven

Carlo JW Leget

Joost Dekker

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Abstract

Based on our empirical research on global meaning in people with spinal cord injury and people with stroke, we formulated 'inner posture' as a concept in rehabilitation. Inner posture, as we concluded from our empirical data, refers to the way in which people bear what cannot be changed. It helps them to live with their injury. Considering that much has already been written about meaning from a variety of disciplines, the question arises whether the concept of inner posture adds something new to the existing literature, or is just another name for a phenomenon that has already been described before in different terms. In this paper, we aim to investigate this and to clarify our conceptualization, by comparing the concept of inner posture with influential concepts in healthcare literature which seem to be more or less related. In the work of Puchalski regarding spirituality, Pargament regarding religion, Eliott regarding hope and Frankl regarding attitude, we found definitions and descriptions that seemed to come close to the phenomenon we refer to as inner posture. Because these concepts have various theoretical backgrounds, the comparison can help to better understand our concept of inner posture, through a process of dialogue between traditions, following Gadamer's notion of dialogue as fusion of horizons of understanding. We conclude that inner posture differs from the other concepts in several ways. Some of these differences are fundamental, other are partial. This suggests that we identified a new perspective on a phenomenon partially described earlier. The comparison also inspired us to slightly adjust our definition and to formulate new research questions.

Introduction

When a person encounters a stressful life event such as a life-threatening disease or an impairment that influences daily life considerably, adjustments need to be made in various areas of life. These may include practical or vocational changes, or changes in social life. As a result, questions of meaning are likely to be evoked.[1-4] The experience of a life changing event confronts a person with discrepancies between how they thought their life was or should be, and how it actually is. This challenges the experience of the meaningfulness of life.

Over the last three decades, the importance of meaning as a resource for living with the consequences of a disease or impairment has been more and more acknowledged.[3,5,6] Instruments have been developed to measure various aspects of meaning.[7-10] Based on a review, Park[3] introduced a meaning-making model in order to structure the literature on meaning. In this model she distinguished two levels of meaning: situational meaning and global meaning. Situational meaning refers to psychological processes of meaning making in specific situations. Global meaning can be seen as the more fundamental, existential level of meaning.[3,4,11-14] Global meaning refers to a person's fundamental beliefs and life goals. It influences thoughts, emotions and behavior. When people try to find meaning in a stressful situation, they turn to their fundamental beliefs and life goals for support. Their global meaning provides a source of motivation and serves as a basis for dealing with the situation. The majority of the literature on meaning focuses on situational meaning (see for example the extensive literature on coping, including spiritual coping,[15-19] and meaning-focused coping[20-22]), and not on the more fundamental level of global meaning.

In previous research regarding people with spinal cord injury and people with stroke, we identified five aspects of global meaning: core values, relationships, worldview, identity and inner posture.[11,12] *Core values* are fundamental beliefs about what is right, and life goals worthy to be pursued, giving direction to thoughts, emotions and behavior. *Relationships* refer to a connection between a person and others, e.g. children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are life goals. *Worldview* is a set of fundamental beliefs about life, death, and suffering, which structure people's ideas on how life events are related. *Identity* refers to fundamental beliefs about one's deepest self, providing people with a sense of belonging, uniqueness and self-worth. *Inner posture* refers to the way in which people bear what cannot be changed, which is an important goal in life. Inner posture includes an element of acknowledgement and an element of choice and action. It involves acknowledging the facts of life and choosing how to relate to them.[23] Four of these aspects (viz. core values, relationships, worldview, and identity) are regularly found in research regarding meaning, or stressful life events.[1-3,24-30] However, to the best of our knowledge, inner posture has not previously been identified.

Since inner posture is not mentioned in the literature, we have looked for similar concepts in literature on meaning and healthcare, in order to better understand the phenomenon it refers to. We identified four concepts that show resemblance to inner posture: spirituality, religion, hope, and attitude. These are complex and controverted concepts. Many researchers, philosophers, poets and mystics throughout time have written about and reflected on them in varying degrees of intensity. However, in the work of Puchalski regarding spirituality,[31,32] Pargament regarding religion,[2] Eliott regarding hope,[33] and Frankl regarding attitude,[34] we found definitions and descriptions of concepts that seemed to come close to the phenomenon we refer to as inner posture. In the present paper, we aim to clarify our conceptualization of inner posture, and to determine whether the concept of inner posture adds something new to the existing literature, by relating it to the abovementioned concepts, as presented by the abovementioned authors.

Gadamer's hermeneutics

Since our question is a hermeneutic one: 'what is this phenomenon, that we refer to as inner posture?', our approach in this paper is informed by Gadamer's notion of hermeneutic understanding. Gadamer's hermeneutics addresses knowledge, and the understanding of (historical) texts. His hermeneutics is informed by Plato's idea of the centrality of dialogue as the means by which we come to an understanding. In the line of Heidegger, he states that "all understanding is ultimately self-understanding".[35] He describes understanding as a dialogue between the interpreter and the text, in which ideally both parties are changed. He describes the essence of understanding as follows: "... understanding an expression means, ultimately, not only immediately grasping what lies in the expression, but disclosing what is enclosed in it, so that one now knows this hidden part also".[35] In this process, the interpreter does not only understand the meaning of the text, but comes to a better understanding of themselves as well.

Understanding, in Gadamer's idea, involves a 'fusion of horizons'. Each time, each text, each concept, and each interpreter has their own horizon of understanding. In understanding a (historical) text or a concept, the text or concept itself is involved, as well as the interpreter's comprehension of it. "Part of real understanding is that we regain the concepts of a historical past in such a way that they also include our own comprehension of them".[35] This requires a fusion of the horizons of the text and of the interpreter.

For Gadamer, a dialogue focuses not on a subjective understanding of the other party, but on the subject matter, on which both parties want to come to an agreement. In a true dialogue, both parties show openness and willingness to be changed. "To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one's own point of view, but being transformed into a communion in which we do not remain what we were.".[35]

Approach

In this paper, we intend to explore the phenomenon we refer to as inner posture, by initiating a dialogue between the concept of inner posture and four influential concepts in healthcare literature, as presented by specific authors. We acknowledge that each concept has its own horizon, or context. We describe our concept of inner posture, as well as the concepts of spirituality,[31,32] religion,[2] hope,[33] and attitude,[34,36] from within their contexts. After each description, we start with identifying communalities with our conceptualization of inner posture. Subsequently we identify differences between inner posture and the related concept in question, and investigate how each of the concepts sheds a different light on the issue at stake. Thus, we explore possible relationships between the concept in question and inner posture, aiming to foster a dialogue between inner posture and the related concepts and their respective traditions. The dialogue between the concepts and their traditions is intended to better understand the phenomenon of inner posture, and determine both its novelty and the relationship with more familiar notions.

Comparison of concepts

Inner posture

In 2012, our project titled 'Searching for continuity: changes in global meaning in people with spinal cord injury or people with stroke' started, in a Dutch rehabilitation center. This was a first exploratory study on global meaning in the field of rehabilitation and healthcare chaplaincy. Chaplains support people when the self-evident order of everyday life is broken; in situations of life and death, in the event of farewell and loss, in the case of experiences of great connection or of abandonment, and in ethical questions. They are proficient in dealing with life questions, meaning, spirituality and ethical considerations.[37] One of the goals of the project was to describe the content of global meaning in people with spinal cord injury and people with stroke. In this qualitative project, five aspects of global meaning were found: core values, relationships, worldview, identity and inner posture,[11,12] the latter being a new concept, not previously found in literature. The phenomenon respondents referred to, concerned the way they related to the facts of life: to the positive ones, but also to their injury, each in different ways. When confronted with challenging consequences of their injury, respondents tended to encourage or to calm themselves with spiritual exercises such as prayer or meditation, or they reminded themselves of what they had learned earlier in life. For some, it involved relying on their identity as a strong person, or on core values such as taking responsibility for one's actions and choices, or caring for other people. For others, it was connected to their relationships, reminding them that they still were loved and valued, or to their worldview, that for instance God challenges us to make the best of life and of ourselves. In most cases, this helped them to bear the challenges of living with spinal cord injury or stroke. The context of the rehabilitation center, being strongly focused on physical recovery, inspired us to

choose a physical term to describe this phenomenon: inner posture. Significantly, during the interviews, the researcher observed that respondents often changed their physical posture, when referring to this non-physical (hence: inner) phenomenon.
Since the concept of inner posture was not found in existing literature, there is a need for further exploration. By comparing the concept to four other concepts which seem to address similar phenomena, we aim to get a better understanding of the concept and the phenomenon that it refers to.

Inner posture and spirituality

In 2004, the U.S. National Consensus Project for Quality Palliative Care defined eight domains of care, among which spiritual, religious and existential issues. The identification of spiritual care as an integral part of whole person care turned out to be difficult, due to a lack of models, practical tools, diagnostic criteria and interventions for spiritual distress. In 2009, a Consensus Conference was held in California, which aimed at exploring how these difficulties could be addressed. In this conference, a consensus definition of spirituality was developed. This definition, presented by Puchalski and others, is as follows:

> 'Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.'[31]

In 2013, a global definition was developed in an International Conference on Improving the Spiritual Dimension of Whole Person Care:

> 'Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose and transcendence and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.'[32]

Searching for similarities between the concept of spirituality and the concept of inner posture, we see that both inner posture and spirituality seem to be relevant to life in general, but are foregrounded in stressful times. People turn to resources such as spirituality when the self-evidence of life is challenged and questions of meaning are evoked, in extremely negative or extremely positive circumstances.[31] Inner posture concerns bearing all facts of life, the positive and the negative ones, but is specifically evoked in stressful circumstances such as a life changing disease or handicap.[11,12]

Another similarity is a combination of activity and receptivity in both spirituality and inner posture. Spirituality involves seeking and expressing meaning and purpose, and experiencing connectedness. Seeking and expressing seem to describe an active action, which the person may choose to undertake or not, whereas experiencing seems to point to a more receptive side of spirituality. Inner posture concerns bearing the facts of life. On the one hand, this involves actions, but it also entails receptivity, endurance and passivity.

In addition, spirituality is not an entirely internal aspect of humanity, but it is expressed through beliefs, values, traditions, and practices. Similar to spirituality, inner posture can be expressed and shown as well. That is, inner posture can be expressed in thoughts or behavior that may be strictly personal or may be shared with others, e.g. spiritual exercises such as prayer or meditation. When the expression of inner posture takes the form of spiritual exercises, it seems to overlap with the expression of spirituality.

However, there are differences as well. Spirituality is involved in seeking meaning and connectedness, whereas inner posture concerns 'bearing the facts of life'. This seems to suggest a difference in aim: spirituality aiming at seeking (meaning and connectedness) and inner posture at bearing (the facts of life). Nevertheless, seeking meaning and connectedness can be seen as a way of bearing the facts of life, amongst other ways. In that case, spirituality could be part of one's inner posture.

Besides that, the definitions of spirituality describe a relation to 'the moment, self, others, nature, and the significant or sacred' (2009) or 'self, family, others, community, society, nature, and the significant or sacred' (2013). Inner posture, however, is involved in (bearing) the facts of life. This suggests a difference in scope. The scope of inner posture are the facts of life, all facts of life, although particularly in more challenging circumstances. The scope of spirituality is one of transcendence. Spirituality is engaged in seeking and expressing meaning and connectedness with entities transcending the mere facts of life, such as the moment, nature, or the sacred.

In addition, there seems to be a difference in temporal dimension between spirituality and inner posture. Seeking ultimate meaning, purpose and transcendence, spirituality seems to be engaged with the future, at the same time being engaged in the present, when experiencing connectedness with the moment, self, and nature. Spirituality can be expressed, amongst other things, through traditions. This suggests an orientation on the past as well. Inner posture on the other hand, is oriented on bearing the facts of life in the present. There is no possible way of bearing the facts of life in the past or in the future. Bearing always takes place in the present.

Another difference is that in spirituality connectedness or relationship is an important element. In this respect, there is a difference with inner posture, which is more personal and individual. Relationships are related to, but conceptually distinguished from inner posture, since both inner posture and relationships are aspects of global meaning.
Besides that, whereas inner posture is an attribute of the person, spirituality can also be evoked in or connected with certain situations, for example the experience of connectedness with nature. Inner posture is a personal and embodied concept, whereas in spirituality the context can also play a role. An experience requires a context in which the experience takes place.

Also, spirituality seems to exceed the individual level, in that it refers to an intrinsic aspect of humanity. This raises the question whether inner posture can also be seen as an intrinsic aspect of humanity, in the way that every person has an inner posture.

Finally, in spirituality, experience seems to play an important role. Through spirituality, people seek ultimate meaning, and experience relationship with self, others, or the sacred. Both seeking and experiencing seem to be equally important in the definition of spirituality. Experience is not mentioned in our definition of inner posture.

This raises questions regarding the relation between inner posture and experience. A person's inner posture may be shaped by their experience, and be changed or adapted by it. The opposite is also possible: that a person's inner posture shapes their experience. However, these are questions that require more in-depth research and reflection, which would exceed the scope of this paper.

All in all, spirituality and inner posture seem to describe different, but related phenomena (see Table 1).

Inner posture and religion

Pargament describes religion in relation to psychological coping with stressful life events. He observes that, when people are challenged by stressful life events, many tend to reflect on these events in religious terms. He emphasizes the role of religion when people are put to the test, and states that 'in periods of crisis religion can be intimately involved'.

When defining religion, he states that

> 'Religion can be seen as a process, a search for significance in ways related to the sacred. ... Religion offers people a pathway to follow in the search for significance. However different, all pathways involve feeling, thinking, acting and relating. ... In the face of crisis, we are guided and grounded by an orienting system. The orienting system is a general way of viewing and dealing with the world. It consists of habits, values, relationships, generalized beliefs and personality. ... While different religions envision different solutions to problems, every religion offers a way to come to terms with tragedy, suffering and the most significant issues in life.'[2]

When we search for similarities between religion and inner posture, we see that both religion and inner posture are engaged in life in general, but are specifically evoked in challenging circumstances, albeit that religion, just like spirituality, is also engaged in peak experiences.

Besides that, both religion and inner posture have an expressive component: religion involves thinking and acting, generally taking the form of religious rituals, which corresponds to the prayer and meditation, and the reminding oneself of what one has learned earlier in life, that may be the expression of a person's inner posture. Some people express their inner posture in religious actions such as prayer, but others find their own secular ways. This suggests that religion may represent a broader context in which inner posture can function.

In addition, religion has an active as well as a receptive side. When religion is described as a process, a search, involving acting, and habits, this seems to indicate an active side of religion, which corresponds to the active bearing that inner posture entails. However, as bearing can also take a more receptive and passive form, religion seems to have a more receptive side as well: habits, personality, feeling and relating can be active as well as receptive or passive.

Considering the differences between religion and inner posture, we see a difference in aim: religion aims at searching (for significance) and inner posture at bearing (the facts of life). In some people, however, bearing can take the form of searching for significance, whereas in others it can take all kinds of different forms.

Another difference regards the orientation towards the sacred in religion. The scope of inner posture is the facts of life, whereas the scope of religion, the sacred, transcends the mere facts of life.

Also, religion is described as a general way of viewing and dealing with the world, including values, relationships, generalized beliefs and personality. Like in the case of spirituality, relationships are seen as being a part of religion. This is different in inner posture: relationships are conceptually distinguished from inner posture, as are values, and personality. Relationships, core values, worldview, identity and inner posture are all aspects of global meaning. In this respect religion seems to correspond with global meaning in general.

Besides that, religion offers a pathway external to the person, whereas inner posture is an intrapersonal phenomenon. Also, the form religion takes is often determined by the context in which it functions. It takes different forms in e.g. different cultures. In this respect religion is contextual, in that it is shaped by external influences, although it can take individually different personal forms as well.

Finally, there seems to be a difference in temporal dimension between religion and inner posture. Inner posture is concerned with bearing the facts of life in the present, whereas religion is also concerned with the past and the future. A search for significance in ways related to the sacred indicates an orientation on a desired future in which significance may be found. Often, this search is guided by rituals and lessons handed down by past generations or based on one's own experiences.

All in all, religion and inner posture seem to delineate related, but different phenomena (see Table 1). Religion seems to correspond to global meaning in general, and not to inner posture in particular.

Inner posture and hope

Hope is an important element in the rehabilitation context.[38-44] Although there are various definitions of hope, a common understanding is that it influences rehabilitation outcomes[42] and psychological adjustment.[41,43,45] One of the researchers on hope, although not in rehabilitation, is Eliott. Eliott studied the use of the word hope and its derivatives in the language of people with cancer. She describes hope as

> 'a personal attribute gained through connection with others. It enables individuals to resist despair. ... Hope is a dynamic resource that assists patients to cope better and to find meaning in their experiences. Some suggest that hope is prompted by, and inextricably linked with, negative events such as the presence or threat of loss or despair, simultaneously offering the resources to overcome or endure these.'[33,46]

Eliott distinguishes between hope-as-noun and hope-as-verb, and states that

> 'hope-as-verb positions the patient as actively engaged in their circumstances, working to establish and confirm patients' agency, and to facilitate the envisaging of a possible positive future. It implies an active occupation in the present time, but the focus might be on another time or another life', either the patient's or that of a loved one.[5,33]

When we compare hope and inner posture, we find that both seem to be helping people to live with whatever life brings them. The scope of both hope and inner posture regard the facts of life, albeit that hope focuses more on challenging facts, whereas inner posture involves positive as well as negative facts of life.

Besides that, hope-as-verb is described as active, and confirming patients' agency, but it may also take a more receptive and passive form of hoping and waiting. This resembles the active as well as receptive forms inner posture may take.

Finally, a partial similarity between hope and inner posture is, that hope-as-noun seems to be more of an attribute of the situation, whereas hope-as-verb can be seen as an attribute of the person. A person may hope (verb) something, or there may be hope (noun) in a certain situation. Hope-as-verb resembles inner posture in that both can be seen as personal and embodied concepts. In this respect hope seems to be both personal and contextual, whereas inner posture is also personal, but not contextual, since it is not an attribute of the situation. Also, a person's inner posture denotes a tendency to act (or refrain from acting) in a certain way, that is the same in different contexts, and not defined by the situation.

A difference between hope and inner posture is, that hope seems to be aimed at a change of the present in favor of a better future, and inner posture is focused on bearing the facts of life in the present moment, or in general. This suggests a difference in aim: hope aims at change and inner posture aims at bearing. It also points to a difference in temporal dimension. Inner posture is engaged in the present, whereas hope can be oriented to the present, but may also be concerned with another time, and a possible positive future.

This future may be the patient's own future, or that of a loved one,[33] which suggests that connectedness and relations are important in hope. This suggestion is supported by the fact that hope is described to be gained through connection with others. Connectedness with other people seems to be an important aspect of hope, whereas inner posture is more individual, as we have also seen in the comparisons with spirituality and religion. Finally, hope enables individuals to resist despair and it assists patients to cope better and to find meaning in their experiences. Hope is described to be elicited in circumstances of loss and despair. Inner posture, however, plays a role in life in general, although it is foregrounded in stressful times.

All in all, hope and inner posture seem to address different but related phenomena (see Table 1).

Inner posture and attitude

A well-known statement of Viktor Frankl is:
'the last of human freedoms is to choose one's attitude in any given set of circumstances.'[34]
Being imprisoned in a concentration camp in World War II, he had seen people suffer, had suffered himself and reflected on the differences between prisoners who were and those who were not able to bear the horrors of the concentration camp life. He concluded that it was the attitude of the prisoner in question that made the difference. After the war, he developed logotherapy, a form of existential analysis, aimed at supporting people in finding meaning in life. He says that
'a human being, by the very attitude he chooses, is capable of finding and fulfilling meaning in even a hopeless situation'.
He states that
'there are three pathways to meaning: (a) giving or contributing something to the world through our work, (b) experiencing something or encountering someone, and (c) choosing a courageous attitude toward unavoidable suffering.'
According to Frankl, the attitude a person can choose is related to pain, guilt and death.[36]

Linguistically, attitude is more or less a synonym for (inner) posture. Nonetheless, when we focus on content and use of both concepts, we see similarities as well as differences. Frankl speaks of any given set of circumstances, which resembles all facts of life that inner posture is concerned with. However, while inner posture is explicitly involved in positive as well as negative facts of life, attitude is specifically mentioned in relation to (unavoidable) suffering. In his elaboration on the subject, Frankl focuses on the domains of pain, guilt and death. This seems to indicate a partial difference in scope: negative facts of life such as pain, guilt and death (attitude) versus all facts of life (inner posture).

However, there are more similarities. Both inner posture and attitude are engaged in the present moment. It is impossible to choose an attitude in the past or the future, as it is impossible to bear the facts of life in other times than the present.
Another similarity is, that both are not contextual but personal: it is not the situation that defines the shape of the attitude or inner posture, it is the person that has or chooses a certain attitude or inner posture. Furthermore, the attitude a person chooses, or a person's inner posture, are their own. A person's attitude or inner posture is not directly related to other persons. In this respect, connectedness is not central to attitude nor to inner posture. Besides that, both attitude and inner posture aim at bearing whatever a person may encounter. And they do so by choosing how to relate to the facts of life (inner posture) or by choosing their attitude in any given set of circumstances (attitude).

There are also differences between attitude and inner posture. Choosing an attitude is described as an action, whereas choosing involved in inner posture may take more receptive and passive forms as well. Besides that, choosing is not a characteristic of attitude, it precedes the chosen attitude. This implies that the possible attitude that can be chosen seems to be more of a predefined object than is the case with inner posture.

One can choose an attitude. This suggests that there are different attitudes that can be chosen, which is supported by Frankl's use of the plural (attitudes to pain, guilt and death) in his later work. Obviously, the question of how much we choose our attitudes and how we come to them is a very complex matter, that exceeds the scope of this paper. While Frankl states that a person can choose their attitude, inner posture may be seen as an intrinsic personal feature, which implies that it is not something that can be simply chosen, but is likely to be formed and developed during the life span.

All in all, attitude and inner posture seem to describe closely related phenomena that slightly differ (see Table 1). The comparison raises questions on how an inner posture is acquired and on how easily it is chosen or changed.

Discussion and conclusion

In this paper, we reflected on a phenomenon we identified in our research project regarding global meaning in the rehabilitation of people with a spinal cord injury or stroke. We used the term inner posture to describe this phenomenon, and originally defined it as follows: '*Inner posture refers to the way in which people bear what cannot be changed, which is an important goal in life. Inner posture includes an element of acknowledgement and an element of choice and action. It involves acknowledging the facts of life and choosing how to relate to them.*'[12,23]

We related our concept to four widespread and influential concepts found in healthcare literature: spirituality,[5,31,32] religion,[2] hope,[33] and attitude.[34,36]

We described the concepts from within their contexts and compared them on different points, derived from the specific characteristics of the different concepts, as presented by these specific authors. All five concepts are developed by different disciplines in different domains of healthcare. Frankl is an exception in that his initial idea for developing a theory on attitude originated in his experiences in a concentration camp. But his elaboration on the concept took place in the field of psychotherapy, helping people who suffered from psychological and psychiatric problems.

This comparison shows that there are several similarities and differences between inner posture and the other concepts.

All concepts are involved in helping people to live or to cope with the consequences of stressful life events. Inner posture, spirituality and religion are also involved in positive life events, whereas hope and attitude are more restricted to situations of loss, despair or suffering. Inner posture and attitude differ from spirituality, religion and hope in aim (bearing vs seeking/searching or change), the role of connectedness, a personal or contextual perspective, and in temporal dimension. Regarding scope, the difference between inner posture and hope and attitude is only partial, whereas the differences with spirituality and religion are more fundamental (facts of life vs transcendence). Both inner posture and spirituality and religion show an expressive element, which hope and attitude do not.

All in all, inner posture and attitude show most similarities, differing only partially on scope and eliciting experiences and more fundamentally in that attitude seems to show no receptive side and no expressive component. This is summarized in Table 1

All this seems to suggest that with inner posture, we found a new perspective on a phenomenon partially described earlier by other concepts. The comparison evokes insights regarding inner posture that we did not see that clearly before, such as the receptive side of inner posture and its expression. In line with Gadamer's idea of transformation as a result of dialogue, these new insights give rise to reconsider our initial definition of inner posture and to slightly adjust it, taking into account elements which were made explicit through the comparison with the other concepts. This leads us

Table 1: *Overview of similarities and differences between inner posture and the other concepts*

	Inner posture	**Spirituality** (Puchalski)	**Religion** (Pargament)	**Hope** (Eliott)	**Attitude** (Frankl)
Context	Rehabilitation	Palliative care	Trauma care	Healthcare	Concentration camp
Discipline	Chaplaincy and other disciplines	Various disciplines	Psychology	Social sciences	Psychotherapy
Aim	Bearing	Seeking/searching	Seeking/searching	Change	Bearing
Scope	Facts of life (positive as well as negative)	Transcendence (moment, self, nature, sacred)	Transcendence (the sacred)	Facts of life (negative)	Facts of life (negative)
Connectedness	No	Yes	Yes	Yes	No
Personal/ contextual	Personal	Both personal and contextual	Both personal and contextual	Both personal and contextual	Personal
Active/ receptive	Both active and receptive	Both active and receptive	Both active and receptive	Both active and receptive	Active
Expression	Yes (prayer, meditation, reminding)	Yes (beliefs, values, traditions, practices)	Yes (rituals)	No	No
Temporal dimension	Present	Past, present and future	Past, present and future	Present and future	Present
Eliciting experiences	Life in general, but foregrounded in stressful times	Life in general, but foregrounded in stressful times and peak experiences	Life in general, but foregrounded in stressful times and peak experiences	Loss or despair	(Life in general, but specifically) unavoidable suffering

to propose the following adaptation of our definition of inner posture:
'Inner posture refers to the way in which people bear what cannot be changed. It involves acknowledging the facts of life and relating to them. Inner posture can be expressed in thoughts or behavior that may be personal or shared with others in, for example, spiritual or religious practices.'

The differences with the former definition are (1) that the element of choice and action is deleted, to give room to the possibility of the more receptive element; and (2) that the expression of inner posture is added.

The comparison of inner posture with other concepts raises questions that ask for future research, in order to enhance our knowledge of the phenomenon it describes: How is inner posture acquired or developed (as a result of the comparison with attitude)? Is it an aspect of humanity, in the sense that every human being has an inner posture (as a result of the comparison with spirituality)? Is an inner posture something individual, or is it possible to identify certain types of inner postures (as a result of the comparison with attitude, and the possible relevance of spiritual or religious practices for the expressive component of inner posture)? What is the relation between inner posture and experience (as a result of the comparison with spirituality); and what is the relationship with choosing or choice (as a result of the comparison with spirituality and attitude)? (How) can inner posture be changed (as a result of the comparison with spirituality and attitude)?

Conclusion

In the comparison of our concept of inner posture with spirituality (Puchalski), religion (Pargament), hope (Eliott), and attitude (Frankl), we found that inner posture differs from the other concepts in several ways. Some of these differences are more fundamental, other more partial. This suggests that we identified a new perspective on a phenomenon partially described earlier in the literature. The comparison also inspired us to slightly adjust our definition and to formulate new research questions. All in all, we gained more insight in the concept of inner posture as an important element of global meaning. This may contribute to improving healthcare by addressing an important aspect of life that can help people make the best of life in difficult circumstances.

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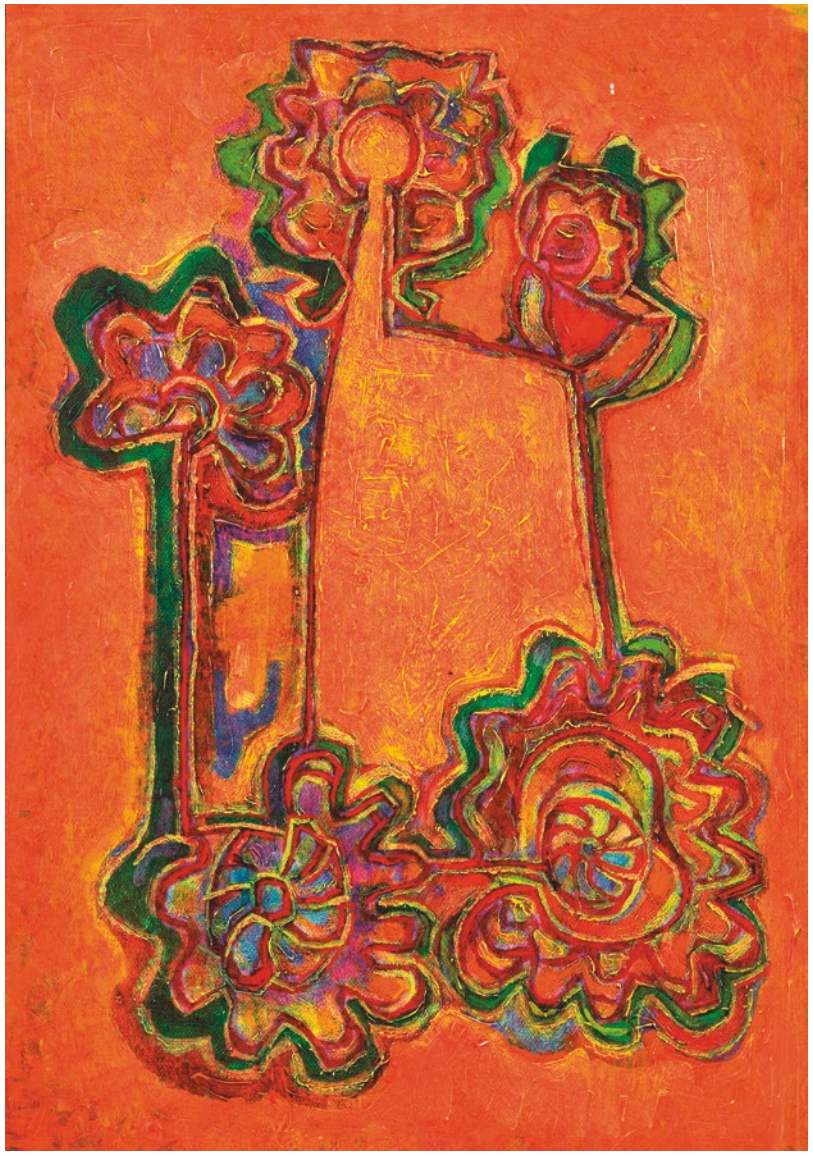

De kinderwagen *In dezelfde periode dat ik mijn beroerte kreeg, onderging onze jongste zoon Sybren een zware rugoperatie. Of hij eruit zou komen met twee verlamde benen was een vrees waarmee ik mee leefde. Sybren zelf zei: 'Mijn lot is allang bij de engelen geschreven'. Bovenbewust aanvaardde hij zelfs een leven in een rolstoel. Zijn chirurg kwam na de zeven uur lang durende operatie lijkbleek en doodmoe met wapperende jas langs om in Sybrens dikke teen te knijpen. Als Sybrens dikke teen gevoelloos was zou de operatie mislukt zijn. Gelukkig bleek zijn dikke teen niet gevoelloos en Sybren hoefde niet te liggen in deze feestelijk uitgeruste kinderwagen! Waar komt deze feestelijkheid vandaan? Door mijn beroerte. De beroerte voerde mij uit mijn lichaam en naar mijn eigen kindertijd. Toen geloofde ik nog jong en eeuwig te leven. Inmiddels ben ik weer afgedaald in het lichaam. Ik besef nu dat mijn lichaam sterfelijk is maar mijn geest is jong en eeuwig.*

Chapter 7

General discussion

General discussion

In this discussion the main findings of the study are summarized. After that, we compare the results in people with spinal cord injury (SCI) and people with stroke. We then discuss several issues that arise from the findings: inner posture in global meaning, global meaning in rehabilitation, global meaning in relation to psychological concepts, and global meaning in relation to religion and spirituality. Next, we discuss methodological considerations and implications for future research. We conclude with implications for future practice, such as the question which professionals should address global meaning in rehabilitation, and which role the chaplain can play in this respect.

Summary of findings

This thesis addresses two related research questions: (i) the content, as well as the perceived continuity or change of global meaning in people with SCI or stroke and (ii) the perceived influence of global meaning on processes and outcomes of rehabilitation according to people with SCI or stroke.

Using a grounded theory approach, we interviewed 16 people with SCI and 16 people with a first stroke. The interviews were loosely structured using a topic list regarding possible aspects of global meaning. The analysis of the interviews was conducted by two researchers, taking field notes regarding the interviewer's impressions and non-verbal aspects of the communication into account. Results were regularly discussed among the other researchers and with the project team.

Research question (i)

Regarding the first research question, we found that global meaning comprises five distinguishable, yet closely related, sometimes intertwined aspects: core values, relationships, worldview, identity and inner posture. We found these aspects in both research groups and in all respondents, regardless their age, sex, cultural background, or the severity or side (in stroke) of their injury. In both groups, respondents reported continuity in global meaning. However, people with stroke reported continuity as well as change in worldview, identity and inner posture (see chapters 2 and 4).

Research question (ii)

Concerning the second research question, both persons with SCI and persons with stroke perceived an influence of global meaning on various processes and outcomes of rehabilitation. Both groups reported influence of global meaning on the processes of motivation, and handling stress and emotions; and they reported influence on the outcome of physical functioning.

Besides that, people with SCI perceived influence of global meaning on the process of

making decisions, and on the outcomes of emotional functioning, social functioning, and a subjective sense of meaning. People with stroke mentioned the additional process of interaction with rehabilitation professionals and the additional outcome of acceptance (see chapters 3 and 5).

Inner posture: a new concept?

Psychological research on SCI and stroke addresses aspects like core values, relationships, worldview and identity. At first sight, this seems to suggest that psychological research does address global meaning. However, on closer observation, it appears that these aspects are in fact mentioned, but not so much as aspects of global meaning. They are described as elements in situational processes. Whereas core values, relationships, worldview and identity as concepts were found in research literature, it seemed that inner posture had not been described earlier. This did lead to the question whether with inner posture we identified a new phenomenon in healthcare or whether it had been described earlier under a different name. We asked ourselves what exactly is this phenomenon we referred to as inner posture, and we sought to clarify and enrich the concept and our understanding of it. We related inner posture to four influential concepts in healthcare literature which seemed to be more or less related: spirituality as defined by Puchalski,[1,2] religion as described by Pargament,[3] hope as presented by Eliott [4,5] and attitude as developed by Frankl.[6,7] We concluded that inner posture differs from the other concepts in several ways. Some of these differences are fundamental, other are partial. This suggests that we identified a new perspective on a phenomenon partially described earlier. The comparison also inspired us to slightly adjust our definition of inner posture (see chapter 6).

Elaboration on findings

Global meaning in people with SCI compared to people with stroke

With regard to the first research question, all five aspects of global meaning were found in both research groups, however, core values and worldview were mentioned less in the interviews with people with stroke. Core values and worldview can be considered aspects that are more cognitive in nature, whereas relationships, identity and inner posture appear to be more emotional and embodied aspects. The changes in cognitive functions that may occur after a stroke could be a reason that people relate less to the more cognitive aspects of global meaning, leading to less emphasis on core values and worldview, and a relative increase in emphasis on the more embodied aspects such as relationships, identity and inner posture.

Regarding continuity or change: after SCI, as well as after stroke, respondents reported continuity in global meaning. However, people with stroke also mentioned possible changes in identity, worldview, and inner posture. This difference may be related to the changes in personality and cognitive functions a stroke may entail. When a person

experiences changes in the way they tend to respond to events and in how they process information, this may challenge their beliefs about who they are (identity), about how life events are related (worldview), and the way in which they can live their life and bear what life brings them (inner posture).

Regarding the second research question, the perceived influence of global meaning on rehabilitation, respondents of both groups experienced an influence of global meaning on various processes and outcomes of rehabilitation. However, people with SCI mentioned more, and more specific, processes and outcomes of rehabilitation. These differences may be related to the fact that after a stroke it takes a longer time to heal, and to reach a balance, if ever (we will elaborate on this below, describing various illness narratives). Or it may have to do with cognitive and personality changes that may appear after stroke, whereas after SCI respondents reported mainly physical and practical changes.

Illness narratives

The differences between the research groups may be related to the way in which people talk about their lives with their injury. Arthur W. Frank differentiates three forms of illness narratives: restitution narratives, chaos narratives, and quest narratives.[8] People who suffer illness, will show all three forms of narratives, but in different proportions. *Restitution narratives* often follow the line of 'I was healthy, now I am ill, but I will be healthy again'. The active agents in restitution narratives are the physicians or the drugs that will make someone healthy again. The ill person shows a preference for the future, when all will be well again. Restitution narratives do not work in situations of chronic disease, when it is obvious that there will be lasting and irreversible changes. In reaction to restitution narratives falling short, chaos narratives or quest narratives may arise. *Chaos narratives* lack the structure of restitution narratives. They mainly speak of a lack of control and show people that speak about themselves without being fully able to reflect on themselves. Other people find these kind of stories difficult to listen to, because of the lack of control and structure. *Quest narratives* circle around searching for alternative ways of being ill. They can evolve out of chaos narratives to hold the chaos at bay. The idea that illness is a journey emerges. An important theme in quest narratives is the thought that something is to be gained from the illness or the injury. The ill person is the agent of their own story. The interruption in their lives is framed as a challenge, an opening to rise on the occasion. Losses continue to be mourned, but the emphasis is on gains.[8]

Although according to Frank people express all three forms of narratives in different combinations, people with SCI emphasized the positive elements they discovered in their new lives, in mentioning more, and more specific processes and outcomes of their rehabilitation. Besides that, they seemed to be more able to reflect on their past and current situations than people with stroke. These are characteristics of quest narratives. The stories of people with stroke were more open-ended, showing more characteristics of chaos narratives.

Inner posture in global meaning

In this project, we described global meaning as 'fundamental beliefs and life goals'. As we said above, we identified five aspects of global meaning: core values, relationships, worldview, identity and inner posture. The first four of these aspects are also found in literature regarding adaptation to SCI or stroke, although primarily on a situational level. The fifth aspect, inner posture, seemed to be a new concept, not previously described. The phenomenon respondents referred to, concerned the way in which they related to the facts of life: to the positive ones, but also to their injury, each in different ways. When confronted with challenging consequences of their injury, respondents tended to encourage or to calm themselves with spiritual exercises such as prayer or meditation, or they reminded themselves of what they had learned earlier in life. For some, it involved relying on their identity as a strong person, or on core values such as taking responsibility for one's actions and choices, or caring for other people. For others, it was connected to their relationships, reminding them that they still were loved and valued, or to their worldview, that for instance God challenges us to make the best of life and of ourselves. In this respect, inner posture seemed to be slightly different from the other aspects of global meaning in that it seemed to be *always* interwoven with the other aspects. Other aspects (i.e. core values, relationships, worldview, and identity) sometimes influenced each other, or they were connected to each other; e.g. values were often related to relationships in the way that an important value could be to take care of one's loved ones. The other aspects could also be found standing alone, whereas inner posture always seemed to be related to one or more of the other aspects.

Besides that, whereas relationships and core values can be seen as life goals, and core values, worldview and identity as fundamental beliefs, inner posture seems to elude the definition of 'fundamental beliefs and life goals'. It seems to be neither a fundamental belief, nor a life goal, although it is based on beliefs and bearing the facts of life can be considered a life goal. In line with Frankl, we suggest that the definition of global meaning could be broadened to include fundamental attitudes, in addition to fundamental beliefs and life goals.

All this raises questions on the place of inner posture in global meaning and its relation to the other aspects. Since this is a first exploratory study on global meaning and inner posture was not previously described, this subject needs more in-depth reflection.

Global meaning in rehabilitation care

In a position paper, the Netherlands Society of Rehabilitation Medicine states that in rehabilitation personal factors of the patient play an important role and should explicitly be taken into account in the treatment plan.[9] Recently, it has been suggested that global meaning (global values and life goals) belongs to personal factors and are likely to influence adjustment to chronic disease.[10]

In our project, respondents made a connection between global meaning and several rehabilitation processes, such as the relationship with rehabilitation professionals. They stressed the importance of global meaning being addressed during their rehabilitation.

They expressed their appreciation of professionals who took e.g. their identity, core values or inner posture into account. Other processes mentioned in both research groups were motivation, and handling stress and emotions. Respondents tended to associate these processes with better or quicker recovery. This could be an indication that better processes lead to better outcomes.

The impact of global meaning on motivation is an important observation in our study. In rehabilitation, motivation is considered a key element.[11-14] Maclean et. al. state that 'the concept [of motivation] is deeply ingrained in the thinking of rehabilitation professionals'.[12] According to Maclean, motivation is seen as an important predictor of rehabilitation outcomes.[12,13] This suggests that future research may focus on the impact of global meaning on motivation in people in rehabilitation. More knowledge on the impact of global meaning on motivation may eventually lead to improved outcomes in rehabilitation.

More specifically, further research may focus on global meaning and goal setting: adequate goal setting is supposed to be a prerequisite for motivation to rehabilitate.[15] We recommend global meaning to be incorporated in the process of goal setting. We propose to develop a tool in which a person's global meaning is one of the leading aspects of goal setting, so that it becomes an integral part of the rehabilitation program. This may contribute to improved goal setting in rehabilitation, and thereby improved motivation for and outcome of rehabilitation.

One outcome that was mentioned by respondents with SCI as well as respondents with stroke, was physical functioning. Besides that, people with SCI mentioned emotional functioning, social functioning, and a subjective sense of meaning, and people with stroke mentioned acceptance. In a review of the theoretical aspects of goal setting and motivation in rehabilitation, Siegert and Taylor indicate that rehabilitation seems to be primarily involved with physical goals, concerned with mobility and physical independence. They suggest that professionals should also be aware of the importance of goals that are more psychological in nature.[14] The various outcomes mentioned by our respondents seem to support their suggestion and go beyond it, in the direction of personally meaningful goals.

Global meaning in relation to psychological concepts

As we said before, four of the aspects we found (core values, relationships, worldview, and identity), seem to be described in psychological research on adaptation to SCI or a stroke, albeit primarily on a situational level.[16,17] For example, the importance of supportive relationships in the adaptation to SCI or stroke is widely recognized.[18-22] These studies focus on the role relationships play in the psychological processes of adapting to SCI or stroke, in other words: they focus on situational meaning, rather than global meaning.

This also applies to the psychological concept of coping.[23,24] Considering psychological studies on coping, several researchers indicate that meaning and spirituality are of influence on coping and adaptation.[25-27] However, most of these studies address situational meaning more than global meaning: coping takes place in a certain situation,

whereas global meaning concerns the more general way of looking at the world, oneself, and the facts of life.

Despite these differences, psychological research seems to show an increasing interest in aspects of global meaning. A specific example is modern personality theory. One of the most recent theories about personality is Dweck's (2015),[28] which integrates motivation, personality and development within one framework, combining different approaches. In this theory, (latent) needs are turned into (active) goals with the help of mental representations: beliefs, emotions and action tendencies (so-called BEATs). These BEATs can be seen as the more latent part of personality. The goals are accompanied or characterized by active acts and experiences. These form the manifest part of personality, or personality traits. Dweck describes personality to be formed and influenced by beliefs and goals. Global meaning consists of fundamental beliefs and life goals. Following Dweck's theory, one could assume that global meaning might play a role in the development of personality and may be a (latent) part of it.

Besides that, Dweck touches upon several aspects of global meaning, when hypothesizing that people's thoughts, emotions and actions are driven by basic needs, such as predictability, acceptance, competence, trust, control, self-esteem/status and self-coherence. Over time, needs can transform into abstractions and generalizations, and become core values. Within self-coherence she distinguishes two sub-needs: identity and meaning. Her use of the concept of meaning comes close to our aspect of worldview: according to Dweck, meaning focuses on the question 'how does or should the world work in ways that matter to me?'.[28]

With this new integrational framework, Dweck seems to address related subjects, that seem to result in concepts similar to global meaning and its aspects. This is a promising development in psychological research.

Global meaning in relation to religion and spirituality

The main part of this thesis consists of five separate articles, publicized in different medical journals. They were written over a period of six years. We related the aspects of global meaning that we found to concepts described in existing healthcare literature. In the process of analyzing the data and writing the articles, we became aware of the complexity and the difference in opinions regarding related concepts. Looking back we see that, especially in our earlier publications, we were not entirely consistent in the use of specific terminology regarding spirituality and religion, for example when we related them to (global) meaning in general, or worldview. In chapter 2, for example, we say that spirituality can be seen as an element of worldview, but that worldview is the more comprehensive term. In chapter 5, however, we say that spirituality can be seen as related to worldview. Since we see worldview as an aspect of global meaning, this raises questions about the relation between global meaning and spirituality as well. In chapter 6, in Puchalski's definition of spirituality, meaning is seen as a part of spirituality. Also in chapter 6, in the comparison of religion with inner posture, we state that religion may represent a broader context in which inner posture can function and in line with that

religion seems to correspond with global meaning in general.

Spirituality, meaning and religion are complex and controverted concepts, as we mentioned in chapter 6. Many researchers, philosophers, poets and mystics throughout time have written about and reflected on them in varying degrees of intensity. This led to several definitions of these concepts and varying descriptions of the relation between spirituality, meaning, religion and worldview.[29] Currently, meaning, religion and spirituality are used differently by different authors and in different contexts. Smeets argues that religion in general functions on the level of what we call worldview.[30] Some authors see spirituality as comprising religion,[31] whereas others, for example Pargament, view religion as broader than spirituality.[3]

Reflecting on this, we see that through the course of this thesis, we could have been more clear in our use of these concepts. As our insights have grown since our work on this project, we currently see the relation as follows: we regard global meaning as the comprehensive term comprising, among other aspects, worldview. A worldview can be religious or non-religious. Spirituality in our vision functions more on the level of global meaning, both presenting a broader framework of beliefs and goals. We differentiate between global meaning and the experience of meaning, and view spirituality as corresponding to both global meaning and the experience of meaning. However, given the complexity of the concepts and the current variation in definitions, further reflection and exploration of the relation between religion, spirituality and global meaning is recommended.

Methodological considerations

Our project was a first exploratory study in the field of global meaning in rehabilitation. In the analysis, it was not always easy to distinguish global meaning from situational meaning. People usually do not have a clearly formulated worldview or identity, and most of them are not able to easily sum up their core values. In the interviews, the interviewer kept asking for underlying goals and beliefs up unto the point where respondents could not answer anymore, and fell silent or started to repeat themselves. Using quotes derived from the interviews, we discussed this issue in the research group. After thorough discussion, we decided that indicators in the data that the level of global meaning was reached, were sudden changes of subject, emotions, silences, and metaphors. In an iterative process, the interviews were adjusted based on this discussion. Although we were able to reach the level of global meaning, further research is needed on the methods that can be used to distinguish situational and global meaning.

We studied global meaning in only two diagnosis groups: SCI and stroke. We do not know if the results are generalizable to other diagnosis groups or the general population. Besides that, the groups of respondents were small. However, in both groups saturation was reached, after 12 or 13 interviews. After that, three or four more interviews were conducted to confirm the assumption that saturation was indeed reached.

Selection bias cannot be excluded: respondents may have had a prior interest in

meaning. We do not have information from the people who did not sent back the consent form to take part in the study on why they did not react.

One of the research questions focused on continuity or change in global meaning. However, the interviews were all conducted after SCI or stroke. Obviously we were not able to interview the respondents before their injury. The interviews therefore reflect the view of the respondents in retrospect. As a result, we cannot be sure if the reported change or continuity is, at least partly, a result of retrospective bias or was affected by memory problems or lack of insight relating to stroke. This problem could partly be addressed by interviewing relatives of the respondents, which may be an interesting field of future research.

The interviews in our study took place in the first period after onset of SCI (6 to 24 months) or stroke (4 to 26 months). We found little (SCI) or some (stroke) change in global meaning. In studies on quality of life after SCI, it was found that between 2 and 5 years changes occur in the ratings persons with SCI give to their subjective quality of life.[32] Although these studies did not address global meaning, this can be an indication that after a longer period of time changes may be reported in global meaning as well. After stroke, it takes a long time to reach a stable situation, if ever. Longitudinal studies are recommended to explore if global meaning changes after a longer period of living with SCI or stroke.

Implications for the future

Implications for future research

Since our study is a first exploratory study of global meaning in the field of rehabilitation, many questions remain that are worth studying. For example, since motivation is a key element in rehabilitation and our study shows a relation between global meaning and motivation, the impact of global meaning on motivation is a promising field of future research. More knowledge on the impact of global meaning on motivation may lead to improved outcomes in rehabilitation.

Because of the importance of professionals addressing the global meaning of their patients, global meaning in (healthcare) professionals would be worth studying as well. How can we expect professionals to address their clients' global meaning, when they are not aware of their own global meaning? And how does a professional's global meaning support their client's global meaning, or interfere with it?

Given the assumption that changes in quality of life may appear longer after SCI and that an end-state after stroke takes longer to be reached, longitudinal studies on global meaning in people with SCI or stroke should be carried out. In order to evaluate changes in global meaning after SCI or stroke, spouses or other family members, or friends of people with SCI or stroke could be studied.

Focusing on global meaning per se, it would be interesting to study how global meaning is acquired or developed. Elaborating on that question, it would be interesting to explore

the role of choice in global meaning. As a person can choose their attitude (as Frankl states), is it possible to choose certain core values, or a particular worldview, or an inner posture?

Also, inner posture could be studied more in detail: what different kinds of inner postures are there? Besides that, there are conceptual questions: is it possible for a person to have more than one inner posture, between which one can choose; is it possible for a group of persons to have a shared inner posture or shared global meaning?

Besides that, we would recommend our findings to be explored in other diagnostic groups and in the general population. Are the five aspects we found specific for the rehabilitation setting, or are they universal? Are there other aspects we did not find? Regarding these questions it would also be interesting to expand the field of research to other environments in which chaplains are engaged, such as general hospitals, or palliative care, but also the army or prisons.

We are only beginning to see what global meaning is and what it can contribute to rehabilitation care, and healthcare in general, so we hope and expect this field of research to grow in the years to come. For example, by focusing on global meaning and goal setting, as we suggested above. Developing a tool to incorporate global meaning in the process of goal setting may improve motivation for and outcome of rehabilitation.

Chaplaincy research

As we said in our introduction, most chaplaincy research concerns the role and efficacy of chaplaincy.[33-36] Besides that, in collaboration with other healthcare professionals, the influence of spirituality and religiosity on health is studied[37-40] and spiritual assessment tools are developed.[41,42] Our study had a different focus. We studied global meaning, which is related to, but to be differentiated from spirituality, and we focused on the impact of global meaning on processes and outcomes of rehabilitation, and not on chaplaincy per se. A more elaborate study of global meaning, as suggested above, would be a valuable addition to the already growing body of research in this field. Especially in Western Europe, where religiosity is less embedded than in other parts of the world, there seems to be a need for more comprehensive and less with religion associated terminology.

Implications for future practice

Since our respondents indicated that attention to their global meaning was important, it is recommended that attention for global meaning becomes an integral part of the rehabilitation program. Ideally, all rehabilitation professionals should take global meaning into account in their treatment. Awareness of the importance of global meaning, of their own global meaning and how this may correspond or interfere with their patient's global meaning, would be a great start. In fostering that awareness, the chaplain could play an important role. They are specialists in this field and can provide training and support for their colleagues in other disciplines.

Training and support can take different forms. A team training providing basic information about what global meaning entails and how it can be recognized and

operationalized in the rehabilitation process would be a suitable first step. It would also help teams of clinicians in recognizing which questions are best to be addressed by which clinician, including the chaplain. Besides that, the chaplain could help their colleagues become aware of their own global meaning, and support them when they encounter differences in global meaning with their patients, which can cause conflict.

In the clinical rehabilitation centers in the Netherlands, the positions of the chaplains vary from fully integrated in the multi-disciplinary team to completely separated from the other professionals in a free-space/sacred-space model. Both positions have their advantages.

An important characteristic of chaplaincy is the association with transcendence, or a higher power. This is why chaplaincy in many institutions is considered an asylum, a free or sacred space. People are free to discuss anything with a chaplain, knowing that confidentiality is secured. When in contact with a chaplain, a person can reflect on aspects of life that go beyond the rehabilitation program and often even beyond their injury. This is an important aspect of chaplaincy, that should be taken into account, and be operationalized in rehabilitation care.

In some rehabilitation centers this aspect is valued so much, that it is reflected in the position of the chaplain as completely apart from therapy. The healthcare chaplain in such institutions is considered not to be a therapist, but a professional with a special place, apart from the rehabilitation team. This position, although in line with the aspect of transcendence and shelter, carries the danger of the chaplain losing touch with other professionals and meaning being overlooked in the rehabilitation process.

Chaplains who work completely integrated, as a member of the multidisciplinary treatment team, are hierarchically positioned under the responsibility of the rehabilitation physician. Being an integrated part of a team of professionals provides chaplains with the opportunity to foster attention for meaning in the rehabilitation program in a natural and organic way. A danger of this position is, that the chaplain may lose their special characteristic of representing a free or sacred space. The chaplain may become so much part of the team, that their independence and their wider view on all of life and not just the injury, runs the risk of disappearing.

The results of our study suggest that collaboration between chaplain and other clinicians is important in providing effective, personally meaningful rehabilitation care. The most suitable form for this collaboration needs to be established in a discourse with all stakeholders.

Final conclusion

In this study, we opened up a new field of rehabilitation and chaplaincy research. With global meaning, we addressed an important aspect of rehabilitation care. Addressing global meaning may improve rehabilitation care, including outcomes of rehabilitation.

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Summary

After a major physical injury, people are confronted with loss of health and physical abilities. Most people need rehabilitation in order to learn to live with the consequences of their injury. Multidisciplinary teams of professionals help people to find new ways to live with their limitations and to develop new skills in order to adjust to the changes. Besides, or as a result of, the physical challenges, questions of meaning tend to arise when people encounter stressful life events like that. To address these questions, healthcare institutions in the Netherlands are obliged by law to provide or give access to chaplaincy or spiritual counseling. In most cases, however, rehabilitation focuses on physical factors, along with psychological and social adaptation, and considerably less on questions of meaning. This is understandable, since rehabilitation care is based on the biopsychosocial approach of the ICF. Even though this approach is more comprehensive than a strictly medical model, it does not automatically include a dimension of meaning and spirituality. The importance of meaning in rehabilitation is more and more recognized, although research on meaning in rehabilitation is scarce. A better understanding of what meaning can comprise and its role in rehabilitation may be important in supporting people in the process of adaptation to a major physical injury. In our research project, we focused on this somewhat neglected, but important area of rehabilitation.

Chapter 1 introduces the diagnosis groups we focused on, and the concept of global meaning. We focused on two diagnosis groups: spinal cord injury (SCI) and stroke. The consequences of SCI and stroke affect all areas of life and often result in permanent changes that make daily life challenging. People with SCI face mostly physical consequences, whereas people with stroke may be confronted with consequences in the areas of cognition and personality as well. Each person with SCI or stroke reacts to this challenge in their own way. Some adapt seemingly easily, others experience more difficulty adapting, or distract from society. However different, people need to find a way to live a meaningful life again.

The goal of our project was to study global meaning in people rehabilitating from SCI or stroke. The term ‘global meaning’ refers to fundamental beliefs and life goals that guide people in living their lives, help them interpret their experiences and motivate them in their actions. Global meaning can be considered as the more fundamental level and needs to be differentiated from situational meaning. Situational meaning refers to specific beliefs about the traumatic event (appraisals), psychological processes aiming at reduction of distress (‘meaning making’), and the outcome of these processes (‘meanings made’).

This study addresses two related research questions: (i) the content, as well as perceived continuity or change of global meaning in people with SCI or stroke and (ii) the perceived

influence of global meaning on processes and outcomes of rehabilitation according to people with SCI or stroke.

Chapter 2 presents the results of the first part of our project: global meaning in people with spinal cord injury, content and changes. Since little is known about global meaning relating to SCI and whether global meaning changes after SCI, in this chapter we aimed to explore the content of global meaning of people with SCI, and to explore whether or not global meaning changes after SCI.

We conducted in-depth semi structured interviews with 16 people with SCI, who were living in the community, and were receiving outpatient rehabilitation in a Dutch rehabilitation center. Participants were purposively selected to include both men and women, younger and older clients, clients with or without a religious background, and clients with a more optimistic or a more pessimistic attitude (according to the physician in attendance). The interviews were audiotaped and analyzed according to the method of grounded theory.

The analysis resulted in five aspects of global meaning: core values, relationships, worldview, identity and inner posture. Core values are global beliefs about what is right and worthwhile. They give direction to thoughts and behavior. Relationships refer to a connection between a person and others, e.g. children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are life goals. Worldview refers to fundamental beliefs about life, death, and suffering, that structure people's ideas on how life events are related. Identity refers to fundamental beliefs about one's deepest self, about who, rather than what a person is. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth. The fifth aspect, inner posture, refers to the way in which people relate to the facts of life.

Overall, we found little change in the content of global meaning after SCI. However, specific aspects of global meaning were foregrounded after SCI.

Chapter 3 aimed to explore whether aspects of global meaning (i.e. fundamental beliefs and life goals concerning core values, relationships, worldview, identity and inner posture) were associated with processes and outcomes of rehabilitation, as experienced by people with SCI.
In the second part of the interviews with the 16 people with SCI, the questions evolved around the rehabilitation process and whether the respondents thought that their global meaning affected the process and outcome of their rehabilitation.

We found that core values, relationships, worldview, identity and inner posture were associated with various processes and outcomes of rehabilitation. Elements of the rehabilitation process included motivation, regulation of emotion, making decisions, and handling stress. Elements of the outcome of rehabilitation included physical functioning, emotional functioning, social functioning, and subjective sense of meaning. We found that the influence was positive, with the exception of one case in

which worldview and inner posture were negatively associated with motivation. Besides that, respondents emphasized the importance of rehabilitation professionals attuning to their global meaning.

In the conclusion of this chapter, it is recommended that rehabilitation professionals are aware of the importance of global meaning to people with SCI and that they take people's fundamental beliefs and life goals into account.

Chapter 4 reports about the second part of our study: the content of and changes in global meaning in people with stroke. This chapter aims to explore global meaning in people with stroke and to explore whether global meaning changes after stroke.

In order to answer the research questions, we conducted in-depth semi structured interviews with 16 people who sustained a stroke for the first time. They had been discharged from the rehabilitation center, and were in outpatient rehabilitation. Participants were purposively selected to include both men and women, younger and older clients and clients with or without a religious background. Clients with severe communication problems were excluded. The interviews were analyzed using the method of grounded theory, using the interviewer's impressions, recorded in field notes as background material. Although previous research on people with SCI had already shaped ideas about global meaning, the researchers who analyzed the interviews were especially focused on the possibility that the interviews with people with stroke might provide different outcomes. Therefore, as customary in grounded theory, the initial interviews were open coded, close to the text, in order to find aspects of global meaning and change in global meaning.

Nevertheless, the same five aspects of global meaning were found: core values, relationships, worldview, identity and inner posture. Both continuity and change were found in global meaning, according to people with stroke. Continuity in all aspects was reported, but worldview, identity and inner posture were also subject to change. Continuity and change were found not to be mutually exclusive, but appeared to co-exist. The change in global meaning found in people with stroke contrasts with the results of our study on global meaning in people with SCI, in which no prominent changes were found. This may be a result of the fact that after stroke it takes a longer time to reach an end-state, compared to SCI. Or it may be related to the fact that the consequences of SCI are mostly physical, whereas stroke can have consequences in the areas of cognition and personality as well.

Chapter 5 describes the perceived influence of global meaning on processes and outcomes of rehabilitation, according to people with stroke. The aim of this chapter was to explore whether global meaning is associated with processes and outcomes of rehabilitation, as experienced by people with stroke.

All aspects of global meaning were associated with the following elements of process and outcome of rehabilitation: motivation, handling stress and emotions, interaction with rehabilitation professionals, physical functioning and acceptance. The influence

was mostly positive. If rehabilitation professionals took global meaning into account, respondents tended to associate this with quicker or better recovery. This suggests that it is important for rehabilitation professionals to address their patients' global meaning. Addressing global meaning may lead to greater patient satisfaction and better rehabilitation care.

Chapter 6 focuses on one of the aspects of global meaning: inner posture. Based on our empirical research on global meaning in people with SCI and people with stroke, we formulated 'inner posture' as a concept in rehabilitation. Inner posture, as we concluded from our empirical data, refers to the way in which people bear what cannot be changed. It helps them to live with their injury. Considering that much has already been written about meaning from a variety of disciplines, the question arises whether the concept of inner posture adds something new to the existing healthcare literature, or is just another name for a phenomenon that has already been described before in different terms. In this chapter, we aimed to investigate this and to clarify our conceptualization, by comparing the concept of inner posture with four influential concepts in healthcare literature which seem to be more or less related to our concept of inner posture. For each concept, we focused on one author. The four concepts (and authors) are spirituality (Puchalski), religion (Pargament), hope (Eliott) and attitude (Frankl). Because these concepts have various theoretical backgrounds, the comparison can help to better understand our concept of inner posture, through a process of dialogue between traditions, following Gadamer's notion of dialogue as fusion of horizons of understanding. We described each concept in its own context and related it to our concept, to explore how each concept can shed light on the phenomenon addressed in our concept of inner posture. We concluded that inner posture differs from the other concepts in several ways. Some of these differences are more fundamental, other are partial. This suggests that we identified a new perspective on a phenomenon partially described earlier. The comparison also inspired us to slightly adjust our definition and to formulate new research questions.

Chapter 7 discusses the findings of the study and elaborates on them. We describe the differences between the two research groups, and discuss that these may be related to the way in which people talk about their lives with their injury. We relate this to Arthur W. Frank's theory on illness narratives.

After that, we discuss inner posture in relation to the other aspects of global meaning. Inner posture seems to be always interwoven with the other aspects, whereas the other aspects can also be found standing alone. Besides that, it seems to be neither a fundamental belief, nor a life goal, although it is based on beliefs and bearing the facts of life can be considered a life goal. This suggests that the definition of global meaning could be broadened to include fundamental attitudes, in addition to fundamental beliefs and life goals.

Next, we describe global meaning in rehabilitation care. The impact of global meaning on motivation is an important observation in our study. In rehabilitation, motivation is

considered a key element. Motivation is seen as an important predictor of rehabilitation outcomes. This suggests that future research may focus on the impact of global meaning on motivation in people in rehabilitation.

After that, we focus on global meaning in relation to psychological concepts, such as coping, and personality. We describe how modern personality theory is showing an increasing interest in aspects of global meaning.

This chapter concludes with methodological considerations and implications for future research and practice. We recommend developing a tool to incorporate global meaning in the process of goal setting, in order to improve motivation for and outcome of rehabilitation. Besides that, we recommend that rehabilitation professionals receive training in order to enhance awareness of the importance of global meaning, of their own global meaning, and how this may correspond or interfere with their patient's global meaning.

Finally, we discuss the relation of the healthcare chaplain and the multidisciplinary team: integrated or separated from the team in a free-space/sacred-space model.

In this study, we opened up a new field of rehabilitation and chaplaincy research. With global meaning, we addressed an important aspect of rehabilitation care. Addressing global meaning may improve rehabilitation care, including outcomes of rehabilitation.

Nederlandse samenvatting

Mensen die een ernstig trauma of een ziekte doormaken, krijgen vaak te maken met verlies van gezondheid en fysieke mogelijkheden. De meeste mensen hebben revalidatie nodig om te leren omgaan met de gevolgen van hun aandoening. Multidisciplinaire teams van professionals ondersteunen mensen bij het vinden van nieuwe manieren om te leven met beperkingen en bij het ontwikkelen van nieuwe vaardigheden. Naast de fysieke uitdagingen, of als een gevolg daarvan, komen in veel gevallen ook vragen naar de betekenis ervan naar voren. Om deze vragen het hoofd te bieden, zijn gezondheidsinstellingen in Nederland wettelijk verplicht om geestelijke of spirituele begeleiding aan te bieden of op zijn minst toe te staan. Revalidatie focust over het algemeen op fysieke factoren en op psychologische en sociale aanpassing en beduidend minder op zingevingsvragen. Dit is begrijpelijk, daar de revalidatiezorg gebaseerd is op de biopsychosociale benadering van de International Classification of Functioning, Disability and Health (ICF). Hoewel deze aanpak breder is dan een strikt medisch model, bevat ze niet automatisch een dimensie van zingeving en spiritualiteit. Het belang van zingeving in de revalidatie wordt meer en meer erkend, hoewel wetenschappelijk onderzoek naar zingeving in de revalidatie schaars is. Een beter begrip van wat zingeving kan inhouden en welke rol het kan spelen in de revalidatie kan van belang zijn bij het ondersteunen van mensen in het proces van aanpassen aan een ingrijpende fysieke beperking. In ons onderzoeksproject hebben wij ons geconcentreerd op dit belangrijke maar enigszins verwaarloosde gebied binnen de revalidatie.

In **hoofdstuk 1** introduceren we de diagnosegroepen waarop wij ons geconcentreerd hebben en het concept 'global meaning', oftewel het zingevingskader. We hebben ons beperkt tot twee diagnosegroepen: dwarslaesie en beroerte. De gevolgen van een dwarslaesie of beroerte hebben invloed op alle levensgebieden en hebben vaak permanente veranderingen tot gevolg die het dagelijks leven tot een uitdaging maken. Dwarslaesiepatiënten hebben daarbij vooral te maken met fysieke gevolgen en de aanpassing daaraan, terwijl mensen die een beroerte hebben gehad ook cognitieve of persoonlijkheidsveranderingen kunnen ervaren. Ieder mens reageert op haar of zijn eigen manier op dergelijke uitdagingen. Sommigen lijken zich gemakkelijk aan te passen, anderen hebben hier meer moeite mee of trekken zich terug uit de maatschappij. Hoe verschillend ook, een ieder staat voor de uitdaging om manieren te vinden om het leven weer vorm te geven en zo mogelijk (weer) een betekenisvol leven te leiden.

Onze conceptualisering van zingeving is gebaseerd op twee wetenschappers: Park en Mooren. Park heeft een meaning-making model ontwikkeld, waarin ze het zingevingskader onderscheidt van situationele zingeving. In haar model is het zingevingskader het meer fundamentele niveau van zingeving. Het verwijst naar algemene oriëntatiesystemen, die mensen helpen om het leven te leven. Met situationele zingeving verwijst ze naar zingevingsprocessen in een specifieke situatie.

Mooren onderscheidt drie niveaus van zingeving: het zingevingskader, het zingevingsproces en de zinervaring. Het onderscheiden van drie niveaus van zingeving helpt ons om zicht te krijgen op de verschillende manieren waarop zingeving in de literatuur wordt benaderd.

Het zingevingskader bestaat uit fundamentele overtuigingen en levensdoelen. Het doel van ons onderzoek was om het zingevingskader te bestuderen van mensen met een dwarslaesie of een beroerte. We behandelen twee, onderling samenhangende, onderzoeksvragen: (i) de inhoud en de ervaren continuïteit of verandering van het zingevingskader van mensen met een dwarslaesie of beroerte, en (ii) de invloed van het zingevingskader op processen en uitkomsten van de revalidatie, in de ervaring van mensen met een dwarslaesie of beroerte.

In **hoofdstuk 2** presenteren we de resultaten van het eerste deel van ons project: de inhoud en (eventuele) veranderingen van het zingevingskader van mensen met een dwarslaesie. Er is weinig bekend over het zingevingskader in relatie tot dwarslaesie, en of het zingevingskader verandert of stabiel blijft na een dwarslaesie. Daarom was ons doel in dit hoofdstuk het verkennen van de inhoud, inclusief eventuele veranderingen, van het zingevingskader van mensen met een dwarslaesie.

We hebben semigestructureerde diepte-interviews gehouden met 16 mensen met een dwarslaesie, die zelfstandig woonden en in poliklinische revalidatie waren in een revalidatiecentrum in Amsterdam. Participanten werden doelgericht geselecteerd, om zowel mannen als vrouwen, jongere en oudere mensen, met of zonder religieuze achtergrond, en met een (volgens de behandelend arts) meer optimistische of pessimistische levensinstelling te kunnen includeren. Tijdens en na de interviews maakte de onderzoekster notities over de observaties die ze deed voor, tijdens en na het gesprek. Deze betroffen details van de interviewsituatie en aspecten van non-verbale communicatie. De interviews werden opgenomen en geanalyseerd volgens de methode van de gefundeerde theoriebenadering.

De analyse resulteerde in vijf aspecten van het zingevingskader: kernwaarden, relaties, wereldbeeld, identiteit en innerlijke houding. Kernwaarden zijn basisovertuigingen over wat juist is en van belang. Ze geven richting aan gedachten en gedrag. Relaties verwijzen naar een bepaalde verbondenheid tussen een persoon en anderen, bijvoorbeeld kinderen, een partner, therapeut of ook een huisdier. Betekenisvolle relaties en de ervaring van verbondenheid zijn levensdoelen. Het wereldbeeld wordt gevormd door fundamentele overtuigingen over leven, dood en lijden. Het wereldbeeld geeft structuur aan ideeën over hoe levensgebeurtenissen met elkaar samenhangen. Identiteit verwijst naar iemands fundamentele overtuigingen over zichzelf, wie iemand ten diepste is. Uiting geven aan hun identiteit geeft mensen een gevoel van verbondenheid met anderen, terwijl het tegelijkertijd iemands uniciteit en eigenwaarde onderstreept. Het vijfde aspect, innerlijke houding, is niet eerder beschreven in wetenschappelijke literatuur. De *term* wordt gevonden in het Boeddhisme en gebruikt in yoga en in de praktijk van de geestelijke begeleiding. Innerlijke houding verwijst naar de manier waarop mensen zich verhouden tot de feiten van het leven.

Over het algemeen vonden we weinig verandering in de inhoud van het zingevingskader na een dwarslaesie. Wel kwamen bepaalde aspecten van het zingevingskader meer op de voorgrond te staan na de dwarslaesie.

Hoofdstuk 3 had als doel om te verkennen of aspecten van het zingevingskader (kernwaarden, relaties, wereldbeeld, identiteit en innerlijke houding) door mensen met een dwarslaesie in verband werden gebracht met processen en uitkomsten van hun revalidatie.

In het tweede gedeelte van de interviews was het gesprek gericht op het revalidatieproces en of mensen dachten dat hun zingevingskader invloed had op processen en uitkomsten van hun revalidatie. De interviewster gebruikte niet precies deze woorden, maar vatte het gesprek tot dan toe samen en vroeg naar de ervaren invloed op de revalidatie. De interviews werden geanalyseerd met kwalitatieve methodieken.

We vonden dat kernwaarden, relaties, wereldbeeld, identiteit en innerlijke houding werden geassocieerd met verschillende processen en uitkomsten van de revalidatie. De verschillende processen waren: motivatie, emotieregulering, besluiten nemen en stresshantering. De uitkomsten waren: fysiek functioneren, emotioneel functioneren, sociaal functioneren en een subjectieve ervaring van zin. We vonden een positieve invloed, met een uitzondering waarin wereldbeeld en innerlijke houding een negatieve invloed hadden op de motivatie.

Daarnaast benadrukten respondenten het belang van het goed aansluiten door revalidatieprofessionals bij het zingevingskader van hun revalidanten. Aan het einde van dit hoofdstuk suggereren we dat revalidatieprofessionals zich bewust zouden moeten zijn van het zingevingskader van mensen met een dwarslaesie en dat ze daar in de behandeling rekening mee zouden moeten houden.

In **hoofdstuk 4** rapporteren we over het tweede deel van ons onderzoek: de inhoud en (mogelijke) verandering van het zingevingskader van mensen met een beroerte. Het doel van dit hoofdstuk was het verkennen van het zingevingskader van mensen met een beroerte en verkennen of het zingevingskader na een beroerte verandert. Om deze vragen te beantwoorden, hebben we semigestructureerde diepte-interviews gehouden met 16 mensen die voor de eerste keer een beroerte hadden doorgemaakt. Ze waren ontslagen uit het revalidatiecentrum en kregen een poliklinische revalidatiebehandeling. Participanten werden doelgericht geselecteerd om zowel mannen als vrouwen, jongeren en ouderen en mensen met en zonder religieuze overtuiging te includeren. Mensen met ernstige communicatieproblemen werden geëxcludeerd.

De interviews werden geanalyseerd volgens de gefundeerde theoriebenadering, waarbij de indrukken van de interviewster, vastgelegd in notities, als achtergrondmateriaal werden gebruikt. Hoewel ideeën over het zingevingskader al enigszins gevormd waren door het eerdere onderzoek onder mensen met een dwarslaesie, waren de onderzoekers die de interviews analyseerden extra gefocust op de mogelijkheid dat de interviews met mensen met een beroerte andere uitkomsten zouden kunnen geven. Daarom werden,

zoals gebruikelijk in de gefundeerde theoriebenadering, de interviews open gecodeerd, dicht op de tekst, om aspecten van het zingevingskader en veranderingen daarin te kunnen vinden.

Desondanks werden dezelfde vijf aspecten gevonden: kernwaarden, relaties, wereldbeeld, identiteit en innerlijke houding. Respondenten gaven zowel continuïteit als verandering in hun zingevingskader aan. In alle aspecten werd continuïteit ervaren, maar wereldbeeld, identiteit en innerlijke houding werden door sommigen ook ervaren als veranderd. Continuïteit en verandering sloten elkaar niet uit, maar leken naast elkaar te bestaan. De ervaren veranderingen in het zingevingskader bij mensen met een beroerte contrasteren met de resultaten van ons onderzoek naar het zingevingskader van mensen met een dwarslaesie. Daarin werden geen opvallende veranderingen gevonden. Dit zou te maken kunnen hebben met het feit dat het na een beroerte langer duurt voor er een eindsituatie is bereikt, in vergelijking met na een dwarslaesie. Of het kan ermee te maken hebben dat de gevolgen van een dwarslaesie over het algemeen fysiek zijn, terwijl een beroerte ook gevolgen kan hebben voor cognitie en persoonlijkheid.

Dit hoofdstuk eindigt met te stellen dat er meer onderzoek nodig is om na te gaan of deze aspecten van het zingevingskader specifiek zijn voor mensen met een beroerte of andere aandoening, of dat ze universeel zijn.

In **hoofdstuk 5** beschrijven we de ervaren invloed van het zingevingskader op processen en uitkomsten van de revalidatie, volgens mensen met een beroerte. Het doel van dit hoofdstuk was om te verkennen of het zingevingskader door mensen met een beroerte in verband gebracht wordt met hun revalidatie.

Het laatste deel van de interviews met de 16 mensen die voor de eerste keer een beroerte hadden doorgemaakt, was gericht op hun revalidatie. Een van de vragen was 'Heeft wat we tot nu toe besproken hebben uw revalidatie beïnvloed? Op welke manier?' De interviewster gebruikte niet precies deze woorden, maar vatte het gesprek tot dan toe samen en ging dan door op de ervaren invloed op de revalidatie.
De interviews werden geanalyseerd volgens kwalitatieve methodes.

Alle aspecten van het zingevingskader werden geassocieerd met de volgende elementen van de revalidatie: motivatie, omgaan met stress en emoties, interactie met revalidatieprofessionals, fysiek functioneren en acceptatie. De invloed was over het algemeen positief. Als revalidatieprofessionals rekening hielden met het zingevingskader, associeerden respondenten dit met een beter en sneller herstel. Dit lijkt erop te wijzen dat het van belang is voor revalidatieprofessionals om aandacht te besteden aan het zingevingskader van hun revalidanten. Dit zou kunnen leiden tot grotere tevredenheid bij revalidanten en betere revalidatiezorg.

In **hoofdstuk 6** richten we ons op een van de aspecten van het zingevingskader: innerlijke houding. Innerlijke houding, zoals we uit onze empirische gegevens geconcludeerd hebben, verwijst naar de manier waarop mensen dragen wat niet veranderd kan worden. Het helpt hen om te leven met hun aandoening. Er is veel geschreven over zingeving vanuit een veelheid aan disciplines. Dat roept de vraag op of het concept innerlijke houding iets nieuws toevoegt aan de bestaande gezondheidszorgliteratuur, of dat het alleen een nieuwe naam is voor een fenomeen dat eerder beschreven is in andere woorden. In dit hoofdstuk is ons doel om dit te onderzoeken en om onze conceptualisatie te verhelderen. Dit doen we door het concept innerlijke houding te vergelijken met vier invloedrijke concepten in de gezondheidszorgliteratuur, die min of meer verwant lijken te zijn aan ons concept innerlijke houding. Voor ieder concept richten we ons op een auteur. De vier concepten (en auteurs) zijn spiritualiteit (Puchalski), religie (Pargament), hoop (Eliott) en attitude (Frankl). Deze concepten hebben verschillende theoretische achtergronden. De vergelijking kan ons helpen om ons concept innerlijke houding beter te begrijpen door een proces van dialoog tussen tradities, volgens Gadamers notie van dialoog als een fusie van verstaanshorizonten. We beschrijven ieder concept in de eigen context, om te verkennen hoe ieder concept licht kan werpen op het fenomeen dat wij innerlijke houding noemen. De dialoog tussen de concepten en tradities helpt ons om het fenomeen innerlijke houding beter te begrijpen en zowel de nieuwheid als de relatie met meer bekende begrippen te bepalen. We concluderen dat innerlijke houding op verschillende manieren verschilt van de andere concepten. Soms gedeeltelijk, soms ook meer fundamenteel. Dit suggereert dat we een nieuw perspectief hebben gevonden op een fenomeen dat gedeeltelijk al eerder is beschreven. De vergelijking inspireerde ons om onze definitie van innerlijke houding op details aan te passen en om nieuwe onderzoeksvragen te formuleren.

In **hoofdstuk 7** bespreken we de uitkomsten van het onderzoek en werken deze verder uit. We beschrijven de verschillen tussen de twee onderzoeksgroepen en suggereren dat deze te maken zouden kunnen hebben met de manier waarop mensen praten over hun leven met hun aandoening. We verbinden dit met Arthur W. Franks theorie aangaande ziekte-verhalen.

Vervolgens bespreken we innerlijke houding in relatie tot de andere aspecten van het zingevingskader. Innerlijke houding lijkt altijd verweven te zijn met (een van) de andere aspecten, terwijl de andere aspecten ook op zichzelf lijken te kunnen staan. Daarnaast lijkt het noch een fundamentele overtuiging, noch een levensdoel te zijn, hoewel het gebaseerd is op overtuigingen en ook het dragen van de feiten van het leven als een levensdoel beschouwd kan worden. Dit suggereert dat de definitie van het zingevingskader uitgebreid zou kunnen worden tot 'fundamentele overtuigingen, levensdoelen en basishoudingen'.

Daarna beschrijven we het zingevingskader in de revalidatiezorg. De invloed van het zingevingskader op motivatie is een belangrijke observatie in ons onderzoek. In de revalidatie wordt motivatie als een sleutel-element gezien. Motivatie wordt gezien als een belangrijke voorspeller van revalidatie-uitkomsten. Dit suggereert dat toekomstig onderzoek zich zou moeten richten op de invloed van het zingevingskader op de motivatie van revalidanten.

Vervolgens focussen we op het zingevingskader in relatie tot psychologische concepten, zoals coping en persoonlijkheid. We beschrijven hoe een moderne

persoonlijkheidstheorie een groeiende interesse in aspecten van het zingevingskader laat zien.

Dit hoofdstuk sluit af met methodologische overwegingen en implicaties voor toekomstig onderzoek en voor de praktijk. We adviseren om een gereedschap te ontwikkelen om het zingevingskader in te bedden in het proces van doelen stellen, om de motivatie voor en de uitkomsten van de revalidatie te verbeteren. Daarnaast zouden revalidatieprofessionals getraind kunnen worden om hun bewustzijn van het zingevingskader van hun revalidanten en van hun eigen zingevingskader te vergroten. Ook zouden zij zich op die manier meer bewust kunnen worden van hoe hun eigen zingevingskader kan overeenkomen of conflicteren met dat van hun revalidanten.

Tenslotte bespreken we de relatie tussen de geestelijk begeleider en het multidisciplinaire behandelteam: geïntegreerd of gescheiden van het team in een vrijplaats-model.

In dit onderzoek hebben we een nieuw onderzoeksgebied geopend binnen het revalidatie- en geestelijke begeleidingsonderzoek. Met het zingevingskader raken we aan een belangrijk aspect van revalidatiezorg. Aandacht voor het zingevingskader zou de revalidatiezorg, inclusief uitkomsten van de revalidatie, kunnen verbeteren.

List of publications and lectures

Publications

Zingeving en dwarslaesie, een kwalitatief onderzoek.
Dwarslaesie Magazine (2014) september
Global meaning in people with spinal cord injury: content and changes
Journal of Spinal Cord Medicine (2016) 39(2), 197-205
The importance of "global meaning" for people rehabilitating from spinal cord injury
Spinal Cord (2016) 54, 1047-1052
Global meaning in people with stroke: content and changes
Health Psychology Open (2016) 3(2), 1-9
Global meaning and rehabilitation in people with stroke
Brain Impairment (2018) 19(2), 183-192
Inner posture as aspect of global meaning in healthcare: a conceptual analysis
Medicine, Health Care and Philosophy (2019) 22(2), 201-209

Lectures

Op zoek naar continuïteit: veranderingen in zingeving na een dwarslaesie of hersenletsel. *VGVZ geestelijk verzorgers in de revalidatie, Doorn, 2013*
Op zoek naar continuïteit: veranderingen in zingeving na een dwarslaesie of hersenletsel. *Neuropsychologen Reade, Amsterdam, 2013*
Op zoek naar continuïteit: veranderingen in zingeving na een dwarslaesie of hersenletsel. *VGVZ geestelijk verzorgers in ziekenhuizen, Amsterdam, 2014*
Zingeving na een dwarslaesie.
Paramedici in de revalidatie, Amsterdam, 2014
Global meaning in people with spinal cord injury.
Revalidatieartsen Noord Holland, Amsterdam, 2014
Existential global meaning in people with spinal cord injury.
DCRM, Rotterdam, 2015
Zingeving en revalidatie na een dwarslaesie.
Mini-symposium onderzoeksprogramma 'Herstel van mobiliteit in de revalidatie van personen met een dwarslaesie', Groningen, 2015
Zingeving na een beroerte. (Hoe) beïnvloedt dat de revalidatie?
Hersenletselcongres, Ede, 2016
Global meaning and rehabilitation in people with spinal cord injury or stroke.
Revalidatieartsen Noord Holland, Amsterdam, 2016
Existential meaning and the rehabilitation team.
DCRM, Rotterdam, 2016
Global meaning in people with spinal cord injury or stroke: content, changes and perceived influence on rehabilitation.
Launch of ERICH, ENHCC, Leuven, 2017

Awards

Duyvensz-Nagel Stichting Fellowship 2012

Revalidatiefonds 2012

VGVZ Science Award 2015

About the author

Elsbeth Littooij is working as a healthcare chaplain and researcher at Amsterdam Rehabilitation Research Center Reade. She studied theology in Utrecht and started her career as a healthcare chaplain at De Lichtenberg (now Beweging 3.0) in Amersfoort. After that, she was a parish pastor in Uithoorn for four years, after which she returned to being a healthcare chaplain at Reade in Amsterdam. She is chair of the association of spiritual caregivers in rehabilitation in the Netherlands, which is a sub-department of the VGVZ, the Dutch association of spiritual caregivers in healthcare institutions.

She was born in 1967 in Dubbeldam as the second of three girls in a Christian Reformed family. Being raised in a loving Christian family, the choice for theology felt as a natural one, even though in the Christian Reformed Churches women aren't allowed to carry the sacred profession. The support of her parents, however, stimulated her to pursue her dream and become a fully ordained chaplain.

Elsbeth has two adult sons and a daughter-in-law, who give her life a lot of meaning. In her free time, she enjoys singing and playing tennis, and spending time with family and friends.

PhD portfolio

Courses	**year**	**ECT's**
Atlas.ti	2012	2
Qualitative Analysis	2013	2
Copen met coping	2013	0,5
Masterclass George Fitchett (+presentation)	2015	1
GWish Summer Institute (+poster)	2016	4
Course on 'Oxford Textbook of Spirituality in Healthcare' and 'The human Quest for Meaning'	2017	7,5
Congresses		
ISCoS Maastricht (poster)	2014	1
ISPRM Berlin (2 e-posters)	2015	2
DCRM Rotterdam (workshop)	2015	2
ESPRM Estoril (oral presentation)	2016	2
ENHCC Debrecen (oral presentation)	2016	2
Hersenletselcongres Ede (workshop)	2016	2
DCRM Rotterdam (workshop)	2016	2
IBIA New Orleans (2 posters)	2017	2
Launch of ERICH Leuven (oral presentation)	2017	2
Classes/supervising		
Co-supervising bachelor thesis	2012	1
Gastcolleges bewegingswetenschappen	2013-2017	2
Co-supervising nurse/researcher	2017-2018	1
Co-supervising physical therapist/researcher	2017-2018	1

Dankwoord

Waar te beginnen? Het is een lange weg geweest. Een mooie weg, soms hobbelig en kronkelig, soms spannend en opwindend, soms taai en zwaar, maar altijd boeiend. Een paar gebeurtenissen en mensen hebben aan de basis gestaan van deze weg. Sander en Wouter, gewoon omdat ze opgroeiden en gingen studeren en ik, rondlopend op de Uithof of de VU, dacht: 'heerlijk, studeren, je hersenen uitdagen, dat mis ik'. Mariska, die vertelde over haar 'nieuwe beste vriendin' Thérèse van Lisieux, en die de opzet van haar promotieonderzoek liet zien. Thomas, met zijn uitdagende 'als je dan zo slim bent, waarom doe je dan geen onderzoek?'. En niet in het minst Jos, die me stimuleerde om, als ik dan toch onderzoek wilde gaan doen, er meteen ook een promotieonderzoek van te maken. Hij wist nog wel iemand die me daarbij kon begeleiden. Zo kwam Joost in beeld. Totaal anders dan ik: psycholoog, man, wetenschapper, een paar jaar ouder. We hebben af en toe flink moeite gehad om elkaar te verstaan. Dat was soms lastig, maar meestal ook heilzaam. Ik moest heel goed uitleggen wat ik bedoelde en niet denken dat woorden en begrippen die voor mij vanzelfsprekend zijn dat voor anderen ook zijn. Heel veel heb ik van jou geleerd, en nog. Daar ben ik blij mee. Naast Joost kwamen Guy en Carlo als (co)promotoren erbij. Ook van jullie heb ik veel geleerd en ik ben dankbaar dat ik met jullie heb mogen samenwerken. Zo ook met de revalidatieartsen die betrokken waren bij dit project: Janneke en Judith. Intelligente vrouwen, die goede vragen stellen en goede feedback geven, heerlijk! Zo'n intelligente vrouw is ook Suzan. Ik ben nog altijd diep dankbaar dat je ooit werkervaring bij Reade wilde opdoen en dat je bent gebleven om het eerste deel van dit project samen te doen. Ook in ons nieuwe project is de samenwerking weer een feestje. Iemand anders met wie ik al jaren goed en fijn samenwerk is Hielke. Dank je voor je niet aflatende belangstelling, steun en meedenken. In dit rijtje hoort ook Ria thuis, die naast ziels-zuster ook mijn Engelse juf was in het begin van het project. Daarnaast mijn ouders en zussen, en de vele collega's, vrienden en vriendinnen, die me steeds weer vroegen hoe het ging en die wilden begrijpen waar ik mee bezig was. Siebe, die me moed insprak en waar nodig stimuleerde om 'mijn darlings te killen' tijdens onze 'inspireren en dineren' (of andersom) etentjes. En natuurlijk Marcel. Je zei dat je er soms niks van snapte waarom ik dit zo graag wilde en niet gewoon lekker parttime werkte en verder tenniste en met vriendinnen koffie dronk... maar dat jokte je. Want je kent me. Dank voor je ruimte en steun, ook hierin. Tot slot dank ik Haar, die mij geschapen heeft, die mij draagt en op mijn voeten zet en die met mij meegaat op mijn levensweg.

After a major physical injury people are confronted with changes in many areas of life. **Elsbeth Littooij** studied global meaning in people with spinal cord injury or stroke.
She interviewed people and asked them about their fundamental beliefs and life goals. These interviews led to fascinating conversations and gave insight in what global meaning can contain and how it affects processes and outcomes of rehabilitation.

The artwork in this thesis is from Herman Smith.
He suffered a stroke at 49 and during his rehabilitation he painted his *'stroke series'*.

Elsbeth Littooij (1967) studied theology in Utrecht and Leiden and works as a healthcare chaplain and researcher at Reade Rehabilitation and Rheumatology in Amsterdam.

Reade
revalidatie / reumatologie